

From the DEPARTMENT OF CLINICAL SCIENCES  
DANDERYD HOSPITAL,  
DIVISION OF CARDIOVASCULAR MEDICINE  
Karolinska Institutet, Stockholm, Sweden

# **COPING AND EMOTIONAL WELL-BEING IN PATIENTS WITH CHRONIC HEART FAILURE**

Catarina Nahlén Bose



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Coping and emotional well-being in patients with chronic heart failure

THESIS FOR DOCTORAL DEGREE (Ph.D.)

by

**Catarina Nahlén Bose**

*Principal Supervisor:*

Professor Fredrik Saboonchi  
The Swedish Red Cross University College  
Karolinska Institutet  
Department of Clinical Neuroscience  
Division of Insurance medicine

*Co-supervisor(s):*

Ph.D. Gunilla Björling  
The Swedish Red Cross University College  
Karolinska Institutet  
Department of Clinical Sciences Danderyd  
Hospital  
Division of Anaesthesia and Intensive Care

Associate Professor Magnus L Elfström  
Mälardalen University  
Academy of Health, Care and Social Welfare  
Division of Psychology

Associate Professor Hans Persson  
Karolinska Institutet  
Department of Clinical Sciences Danderyd  
Hospital  
Division of Cardiovascular Medicine

*Opponent:*

Professor Jan Mårtensson  
Jönköping University  
School of Health Sciences  
Department of Nursing Science

*Examination Board:*

Professor Bengt Fridlund  
Jönköping University  
School of Health Sciences  
Department of Nursing Science

Associate Professor Frieder Braunschweig  
Karolinska Institutet  
Department of Medicine, Solna  
Division of Cardiology

Professor Eva Brink  
University West  
Department of Nursing, Health and Culture  
Division of Advanced Nursing

*“What comes from the heart, goes to the heart”*

*“Det som kommer från hjärtat, går till hjärtat”*

Samuel Taylor Coleridge

# ABSTRACT

**Background:** Chronic heart failure (CHF) is a serious illness, with a profound impact on the patient. Poor health-related quality of life (HRQoL) as well as anxiety and depression are prevalent in CHF and predict mortality and rehospitalization, yet, psychosocial factors are infrequently treated and cared for.

**Aim:** To gather scientific evidence on illness perception and coping strategies to predict emotional well-being in patients with CHF and to establish a measurement model of coping strategies. Furthermore, to evaluate a nurse-led psychoeducational intervention, Coping Effectiveness Training (CET) adapted for patients with CHF.

**Methods:** Studies I-III were cross sectional. Study IV was a randomized controlled trial aimed to improve emotional well-being (one-year follow-up). All studies used patient reported outcome measures and clinical data via medical journals.

**Results:** Younger age and male gender were associated with higher levels of alcohol usage and/or drugs to cope,  $p < 0.01$ . Poor sense of coherence was associated with maladaptive coping (I). A four factorial model of Brief COPE displayed the best psychometric properties (II). Avoidant coping influenced negative affect (NA) (I), worse HRQoL (II) and greater anxiety and depression (III). CET (IV) improved personal control in the intervention group (IG) compared to the control group (CG),  $p = 0.036$ . Improved scores for the IG were detected in emotional well-being and HRQoL,  $p = \text{ns}$ . The IG demonstrated reduced NA,  $p = 0.022$ , excluding cases with clinical anxiety and depression. Time to cardiovascular readmission or death was non-significantly lower in the IG vs the CG (Hazard ratio 0.58 [0.29-1.18]) adjusted  $p = 0.135$ .

**Conclusions:** Personal resources seemed to influence the coping strategies used by patients with CHF. Avoidant coping had an adverse influence on emotional well-being and illness perception in CHF. The perceived sense of control and illness burden were of importance for emotional well-being. A CET intervention for patients with CHF increased sense of control over the illness. CET also reduced NA in patients with no or mild symptoms of anxiety and depression.

**Keywords:** Heart failure; Coping; Illness perception; Emotional well-being; Quality of life; Intervention; Randomized controlled trial

# LIST OF SCIENTIFIC PAPERS

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# LIST OF ABBREVIATIONS

B-IPQ	Brief Illness Perception Questionnaire
CET	Coping Effectiveness Training
CFA	Confirmatory Factor Analysis
CHF	Chronic Heart Failure
CI	Confidence Interval
ESC	European Society of Cardiology
ESSI	ENRICHD Social Support Inventory
HADS	Hospital Anxiety and Depression Scale
HRQoL	Health-related Quality of Life
ITT	Intention To Treat
NA	Negative Affect
NYHA	New York Heart Association
PA	Positive Affect
PANAS	Positive Affect Negative Affect Schedule
PP	Per Protocol
PREM	Patient Reported Experience Measure
PROM	Patient Reported Outcome Measure
RAND 36	Research And Development 36-item health survey
RCT	Randomized Controlled Trial
SEM	Structure Equation Modelling
SOC	Sense of Coherence
QoL	Quality of Life



# 1 INTRODUCTION

Chronic heart failure (CHF) is a serious and incurable illness, shortening the life expectancy of about 26 million people worldwide who are currently living with CHF<sup>1</sup>. The poor prognosis of CHF and rehospitalization rates are comparable to those in the common forms of cancer<sup>2,3</sup>. CHF has been reported to be the leading cause of hospitalizations in patients aged over 65 years<sup>4,5</sup> and the fourth most common reason for all hospital care<sup>4,6</sup>. The economic cost of heart failure care is very high and accounts for one to three percent of the total healthcare expenditure in several countries<sup>1</sup>. The total annual cost of heart failure care per patient in Sweden, including primary health care, has been reported to be €36500<sup>7</sup>.

Individuals living with CHF are affected by the illness in many dimensions of their lives<sup>8</sup>. Patients with CHF experience physical limitations<sup>9</sup>, poor health-related quality of life (HRQoL)<sup>10</sup>, emotional distress<sup>11</sup>, social isolation and existential concerns<sup>12</sup>. Caregivers, such as family members, can also experience distress and social isolation<sup>13</sup>. All of these aspects, and the resulting life style adjustments, challenge the resources of patients with CHF to cope with their life situation<sup>14</sup>.

Over the years, I have cared for many patients with CHF in hospital wards and at a nurse-led heart failure outpatient clinic. It was through my clinical experience that I was inspired to examine coping and emotional well-being in patients with CHF. I observed that these patients coped with their illness in different ways and I wanted to find out what factors could be related to the patients' coping abilities. I decided to investigate this further through research. Later on, the opportunity arose to develop, implement and evaluate an education program for patients with CHF, aimed at enhancing their adaptive coping skills and perception of the illness, in order to improve their life situation. This thesis could contribute to raised awareness and increased knowledge about coping and emotional well-being in patients with CHF and to point towards what kind of support these patients need in order to improve their life situation.

# 2 BACKGROUND

## 2.1 CHRONIC HEART FAILURE

### 2.1.1 Definition, epidemiology and aetiology

Chronic heart failure (CHF) is defined as a syndrome in which the patient has typical symptoms and signs resulting from an abnormality of cardiac structure or function. Typical symptoms of CHF are: shortness of breath, peripheral oedema and fatigue, and typical signs are: elevated jugular venous pressure, pulmonary crackles, and displaced apex beat <sup>15</sup>. The main measurement of the cardiac function is left ventricular ejection fraction (LVEF), i.e. the percentage of blood volume pumped out in systole from the left ventricle, which should normally be > 50 percent. A considerable proportion of patients (40-50%) have CHF with normal LVEF <sup>15</sup>. The severity of symptoms and physical ability is classified in to four functional classes, New York Heart Association Classification (NYHA class) I-IV <sup>15</sup> as displayed in Table 1.

Table 1. New York Heart Association Classification (NYHA class) according to European Society of Cardiology guidelines <sup>15</sup>.

<b>NYHA class I</b>	No limitation of physical activity. Ordinary physical activity does not cause undue breathlessness, fatigue, or palpitations.
<b>NYHA class II</b>	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in undue breathlessness, fatigue, or palpitations.
<b>NYHA class III</b>	Marked limitation of physical activity. Comfortable at rest, but less than ordinary physical activity results in undue breathlessness, fatigue, or palpitations.
<b>NYHA class IV</b>	Unable to carry on any physical activity without discomfort. Symptoms at rest can be present. If any physical activity is undertaken, discomfort is increased.

In developed countries approximately two percent of the population is diagnosed with CHF and the prevalence rises sharply with age where  $\geq 10$  percent of people

over 70 years have CHF<sup>15</sup>. An epidemiological study in Sweden confirmed two percent prevalence and showed that the mean age for an individual diagnosed with CHF was 77 years, where the mean age for women was 80 years and for men 74 years. The incidence was about 3.8/1000 persons per year<sup>16</sup>.

CHF has many primary causes, where the major causes are hypertension and ischaemic heart disease. Other causes could be cardiomyopathy, alcohol abuse and valvular heart disease<sup>15</sup>. Co-morbidities frequently occur in patients with CHF and contribute to increased morbidity, mortality and impaired quality of life (QoL). Common co-morbidities are: chronic kidney disease, diabetes, anemia and depression<sup>17, 18</sup>.

CHF is divided into heart failure with reduced LVEF (HF-REF) and heart failure with preserved ejection fraction (HF-PEF)<sup>15</sup>. Patients with HF-PEF display somewhat different clinical characteristics than patients with HF-REF; they are older, more often female and more likely to have hypertension<sup>19</sup>. HF-PEF is defined by LVEF > 45-50 %, measures of diastolic dysfunction or other objective measures of LV dysfunction, including increased levels of natriuretic peptides<sup>15</sup>.

### **2.1.2 Prognosis**

The five-year survival rate from the first recorded diagnosis of CHF has been found to be 48 percent in the Stockholm region, with two million inhabitants, and was lower than for the age-matched entire Swedish population<sup>16</sup>. Another study from Ireland reported a better five-year survival rate of 64 percent, however, it was lower compared to a non-CHF cohort displaying a survival rate of 80 percent<sup>20</sup>. Patients with HF-PEF have a better survival rate than patients with HF-REF<sup>20, 21</sup>. A decrease in incidence and mortality of CHF has been found over time, which could be attributed to improved treatment and control of risk factors, although the prevalence has remained at the same level<sup>16</sup>. There are many predictors of mortality and hospitalizations in CHF, for example: older age, diabetes, lower LVEF, higher NYHA class and reduced QoL<sup>22, 23</sup>.

Research has shown the trajectory of risk of readmission to hospital and death after being hospitalized for CHF in patients over 65 years. The highest risk of

readmission was within the first two months after being hospitalized, whereas risk of death declined rapidly. In total, the one-year readmission rate was 68 percent and the mortality rate 36 percent <sup>24</sup>. A large global study reported a 30-day hospital readmission rate of 16 percent after being hospitalized for CHF <sup>25</sup>.

The survival rate in CHF is comparable to many cancer diagnoses <sup>3, 26</sup>, yet the trajectory for the end of life for individuals with CHF differs. The typical trajectory is characterized by a gradual decline in function, with intermittent acute worsening of the CHF, followed by a return to near their habitual condition prior to the exacerbation. Eventually, one of these exacerbations will be followed by death. However, death may also come suddenly and unexpectedly <sup>27</sup>.

### **2.1.3 Symptom burden**

CHF exerts an impact on several aspects of the individual's life, such as their physical, emotional, social, intellectual and existential dimensions <sup>8</sup>. The symptom prevalence and symptom burden is high amongst patients with CHF <sup>28, 29</sup>. The prevalence of symptoms has been reported to be as high as a mean of 15 <sup>28</sup> and even up to 19 symptoms <sup>29</sup>, where shortness of breath and lack of energy were the most prevalent symptoms. The majority of the patients also experienced pain <sup>28, 29</sup>. Symptoms perceived as the most burdensome were: shortness of breath, difficulty sleeping, lack of energy and numbness/tingling in hands or feet <sup>28, 29</sup>. Another symptom described as causing suffering is thirst, which is caused by the condition itself as well as the treatment <sup>30</sup>. Emotional distress, such as worrying and feeling sad, has also been reported with high prevalence <sup>28, 29</sup>. Worries could, for example, concern the end of life <sup>12</sup>. Impairment of the patients' cognitive abilities is also quite common <sup>31</sup>.

The physical limitations caused by CHF alerts the individual to find strategies to solve practical tasks in daily life, but there could also be a lack of self-confidence in performing physical activities. The limitation in physical capacity also affects the patient's social role, where their role in society and family is diminished as well as a loss of their social network <sup>9</sup>. A literature review found that men were most bothered with physical limitations causing restrictions to daily activities, whereas

women were most concerned with restrictions interfering with their ability to give support to family and friends<sup>32</sup>. A qualitative study has described the process of becoming a patient with CHF as gradually taking on a new identity and finding meaning with their new life situation. Different phases of this process were identified, starting with a crisis event and ending up in accepting the new life situation, putting it into a context and making lifestyle adjustments<sup>33</sup>.

## **2.1.4 Treatment and care**

There is no cure for CHF, although treatment has certainly made a considerable change for the better for patients with heart failure<sup>34</sup>. Guidelines from the European Society of Cardiology (ESC) state that the treatment of CHF aims to alleviate symptoms and signs of CHF, prevent hospital admission, and improve survival. The non-pharmacological non-device/surgical interventions that have received recommendations with an evidence level are exercise training and implementation of care in a multidisciplinary framework<sup>15</sup>.

### *2.1.4.1 Pharmacological treatment*

The pharmacological treatment recommended for all patients with CHF is angiotensin-converting enzyme (ACE) inhibitors and beta-blockers. An alternative, if the ACE inhibitor is not tolerated, is angiotensin receptor blockers (ARB). The pharmacological base treatment of CHF has proved to improve survival and QoL and reduce hospitalizations<sup>15</sup>. If necessary, the patients also have diuretics to alleviate symptoms. If the patient remains in NYHA II-IV after having been given the base treatment, mineralcorticoid/aldosterone receptor antagonists (MRA) should be administered. The next step in treatment for patients with NYHA II-III, if they have a sinus rhythm with a heart rate  $\geq 70$  beats per minute in combination with LVEF  $\leq 35$  percent, is to give Ivabradine. For patients in NYHA class III-IV, digoxin and hydralazine and isosorbide dinitrate (H-ISDN) could be considered<sup>15</sup>.

### *2.1.4.2 Device treatment*

Cardiac resynchronization therapy (CRT) is recommended for patients in NYHA II-IV who exhibit an LVEF  $\leq 35$  percent, QRS duration  $\geq 120$  milliseconds and a left

bundle branch block <sup>15</sup>. The CRT could also be combined with an implantable cardioverter defibrillator (ICD). The rationale for treatment with ICD is the prevention of sudden cardiac death and can be given both as primary and secondary prevention <sup>15</sup>. Positive outcomes from CRT and ICD in CHF have been found, with improved QoL and reduced hospitalizations and mortality <sup>35</sup>.

#### *2.1.4.3 Surgery*

Coronary revascularization is recommended for patients with CHF who also have angina and coronary artery disease. Valve surgery is an option for patients with valvular heart disease. For patients with end-stage CHF, heart transplantation, could be an option, however, this treatment is for a selected group of patients and the organ donations are limited. An alternative could be mechanical circulatory support, such as left ventricular assist device <sup>15</sup>.

#### *2.1.4.4 Exercise training*

Exercise training for patients with CHF has been shown to improve exercise tolerance, HRQoL and heart failure hospitalization rates and has, via ESC guidelines, received a recommendation class of I with an evidence level of A <sup>15,36</sup>. Despite this high recommendation level exercise training is poorly implemented in the clinical care of patients with CHF. Exercise training can consist of: endurance aerobic training, strength/resistance training and respiratory training <sup>37</sup>.

#### *2.1.4.5 Multidisciplinary management of heart failure care*

Several studies have shown benefits of multi-professional, organized and managed care of patients with CHF <sup>38,39,40</sup>. However, there is no consensus on what the optimal structure for organized management of heart failure care is and it might also differ between countries and regions <sup>41</sup>.

The goal of the management of heart failure care is to provide a chain of care that functions across primary and hospital care, so that the patient with CHF receives optimal care, in order to improve survival and QoL. Essential resources within the heart failure management care are: heart failure specialist cardiologists and nurses, heart failure outpatient clinics and an adherence to common guidelines <sup>41</sup>. The



multi-professional team could also include: physiotherapists, dieticians, primary care providers, social workers, psychologists and pharmacists<sup>42</sup>. Important components in heart failure care are: structured follow-ups with patient education, optimization of medical treatment and psychosocial support as well as improved access to health-care, including palliative care<sup>41</sup>.

#### *2.1.4.6 Nurse-led heart failure clinic*

Specialist heart failure nurses play an important role in the multidisciplinary care of patients with CHF. An important component of the organized care for patients with CHF is nurse-led heart failure clinics<sup>41</sup>. The nurse-led heart failure clinics have shown positive outcomes for patients with CHF with regard to better organized care<sup>43</sup>, improved survival, self-care behaviour<sup>44</sup>, reduced hospital readmissions<sup>45</sup> and functional status, as well as optimal target doses of heart failure medication<sup>46</sup>. A Cochrane review found that case management, i.e. intense monitoring of patients following discharge, with telephone calls and/or home visits by specialist heart failure nurses, to be especially beneficial<sup>40</sup>. The specialist heart failure nurse conducts independent patient consultations where symptoms and signs of CHF are examined through, for example, auscultations of lungs and inspections of oedema. The nurse provides the patient and family members with education on heart failure and self-care according to the guidelines, as well as psychosocial support. Prescribed pharmacological heart failure drugs are up-titrated according to protocol and diuretic doses are adjusted as required. The patients receive a tailored treatment according to what they need and can tolerate. Cardiologists serve as consultants to the nurses<sup>44, 45</sup>.

#### *2.1.4.7 Palliative care*

The aim of palliative care for patients with CHF is to prevent and alleviate suffering and to improve QoL for the patients and their families<sup>47</sup>. Although the poor prognosis and symptom burden is equivalent to cancer<sup>2,3</sup>, patients with CHF are less likely to be supported by hospice and opiates and more likely to die in hospital than patients with cancer<sup>48</sup>. The palliative care in patients with CHF is currently considered to be insufficient and is suggested to be an integral part of heart failure

care <sup>49</sup>. Components of the palliative care are, for instance, to establish an advanced care plan with documentation of the patients' preferences for treatment and resuscitation, identifying end-stage heart failure, and optimizing symptom management at the end of life <sup>47</sup>.

#### 2.1.4.8 *Telemonitoring*

Telemonitoring, remote monitoring and support, of patients with CHF is becoming an increasing part of heart failure care <sup>50</sup>. Telemonitoring could, for instance, involve self-care guidance via a tablet device and weight monitoring <sup>51</sup> as well as wireless implantable haemodynamic monitoring <sup>52</sup>. A meta-analysis of randomized controlled studies with telemonitoring in a Cochrane study found reduced all-cause mortality and, in combination with structured telephone support, a reduction in CHF hospitalizations. In addition, several of the included studies improved QoL and reduced healthcare costs <sup>53</sup>. However, such studies have shown inconclusive results and more research is required <sup>54</sup>.

### 2.1.5 Self-care management

Self-care is defined as the activities an individual carries out in order to maintain life, health and well-being <sup>55</sup>. Orem's theory of self-care has been developed further in to a situation-specific theory of heart failure self-care <sup>56</sup>. The situation-specific theory focuses on three self-care processes: *maintenance* which typically involves treatment adherence, *symptom perception* and *management* which are the responses to symptoms when they occur <sup>56</sup>. ESC guidelines have outlined a description of topics that should be covered in the education of patients with CHF and family members. In relation to these topics knowledge about lifestyle changes alone is not the only goal, but also self-care behaviour and skills <sup>15</sup>. Research has shown that knowledge about heart failure and self-care management is not sufficient in order for the individual to carry out recommendations for making lifestyle adjustments <sup>57</sup>. For example, the patients' emotional state can influence their self-care behaviour <sup>58</sup>, hence there are recommendations to screen for barriers to self-care <sup>50</sup>.

Symptom recognition and symptom monitoring is an integral part of self-care. Symptoms of worsening heart failure could be increasing dyspnea and oedema or a

sudden unexpected weight gain of > 2 kg in three days. If this happens the patient can increase the diuretic dose temporarily and/or contact the health-care. Regular weighing, in order to recognize a potential sudden weight gain, is recommended. A flexible diuretic regime could be recommended, if needed, and requires detailed instructions from the informer <sup>15</sup>. Adherence to the treatment plan is also essential for self-care <sup>15</sup>.

There has been a tradition of advising fluid and sodium restriction to patients with CHF, however, the evidence to support these restrictions are scarce and inconclusive <sup>50</sup>. A study comparing restricted and flexible fluid intake based on weight found no differences, while another study has shown benefits from fluid as well as sodium restriction <sup>59, 60</sup>. The current recommendation for fluid intake is a restriction of between 1.5 - 2 liter/day in patients with severe CHF <sup>15</sup>. A routine fluid restriction is not recommended <sup>50</sup>. Excessive salt intake should be avoided, especially for patients who are symptomatic <sup>50</sup>.

Weight loss should be given attention as it can be a sign of cachexia. Anorexia is a common problem and contact with a dietician might be necessary. It may be advisable to divide daily meals into more frequent but smaller meals. Obesity should also be managed <sup>15, 50</sup>.

Restricted alcohol intake is recommended up to a maximum of two units per day in men or one unit per day in women. A unit is equivalent to one glass of wine for example. However, alcohol abstinence should be advised for patients with alcohol induced cardiomyopathy <sup>15</sup>. Research has shown that moderate wine consumption was associated with better health outcomes for patients with CHF <sup>61</sup>. Ceasing smoking is strongly recommended and the intake of illicit drugs is discouraged <sup>15</sup>. In order to reduce the risk of sleeping disorders obese patients are recommended to lose weight, cease smoking and abstain from alcohol use. For health-care professionals it is important to detect and provide appropriate treatment for sleep-disordered breathing <sup>15, 50</sup>.

Daily moderate physical activity is recommended for all patients with CHF; and for patients with stable CHF exercise training is advised <sup>50</sup>. A concern for many

patients and their partners is sexual activity<sup>62</sup> and research has shown they want information regarding such matters<sup>63</sup>. Individualized counselling is recommended for the patient and their partner to be reassured about engaging in sex and for discussing problems<sup>15, 50</sup>.

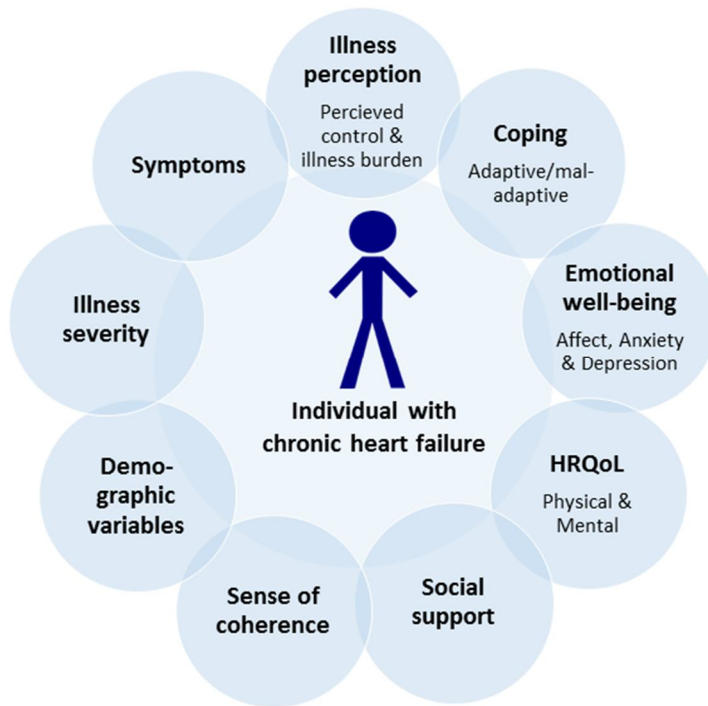
Travel is possible for patients with CHF but may require preparation such as carrying extra medication, medical history records as well as a medication list. When flying, flight socks are advised and fluid intake might need adaption when travelling to hot countries<sup>15, 50</sup>. Patients with CHF are recommended to take immunization against influenza and pneumococcal disease<sup>15</sup>.

Regarding psychosocial aspects it is recommended that patients should be informed that depressive symptoms as well as cognitive dysfunction are commonly associated with CHF. The significance of social support should also be explained<sup>15</sup>. A patient's confidence in undertaking self-care management of CHF, i.e. self-efficacy, is influenced by psychosocial factors<sup>64</sup>. There is limited evidence of the efficacy of psychological as well as pharmacological interventions for emotional distress in the context of CHF<sup>50</sup>. The ESC guidelines are lacking information on how psychosocial support and psychosocial self-care skills could be provided in a systematic manner.

## **2.2 CONCEPTUAL FRAMEWORK**

This section explains the concepts, models and theories that support the conceptual framework in this thesis and reviews the empirical research on how the concepts are manifested in CHF. Figure 1 presents the components of the conceptual framework.

Figure 1. Graphic overview of the components of the conceptual framework of this thesis showing a person with CHF to whom all the components relate to.



## 2.2.1 Emotional well-being

### 2.2.1.1 Definition

The concept of well-being is complex and multidimensional. In the literature, well-being has been described rather than defined <sup>65</sup>. A recent attempt to define well-being defines the concept as a balance point between resources and challenges. Well-being is experienced when the individual's psychological, social and physical resources can meet the demands of a psychological, social and/or physical challenge <sup>65</sup>. The World Health Organization (WHO) refers to well-being in the context of defining health, as *"a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity"* <sup>66</sup>. WHO's definition of health has been critiqued for defining happiness rather than health <sup>67</sup>. The

importance of measuring well-being has become increasingly recognized and well-being has been measured in many European countries at a national level <sup>68</sup>. Moreover, well-being is regarded by the general public to be an important concept to measure <sup>69</sup>.

Emotional well-being, as part of the general concept of well-being, has no clear definition but could be defined as the experience of feeling a pleasant rather than unpleasant affect in one's life <sup>70</sup>. Emotions fluctuate but are suggested to move around a mean level of mood, which differs between individuals. This mean level of pleasant or unpleasant mood, that is stable over time and situations, constitutes the core of an individual's emotional well-being <sup>70</sup>. Furthermore, the frequency of the experience of pleasant affect has more importance than the intensity of the emotions for emotional well-being. This is because intense emotions are rare and people who experience pleasant emotions intensely are also more likely to experience unpleasant emotions intensely <sup>70</sup>. The two-dimensional structure of affect, positive affect (PA) and negative affect (NA) represents the major dimensions of emotional experience <sup>71</sup>. Positive emotions are suggested to contribute to improved emotional well-being <sup>72</sup>. High PA is characterized by feeling enthusiastic, engaged and pleased whereas low PA is a state of feeling sad and lethargic. High NA, on the other hand, regards feelings of distress, anger, fear, guilt and nervousness, and low NA is a state of being relaxed and calm <sup>71, 73</sup>. Both NA and PA can co-occur during chronic stress where PA is of importance for adaptive functions <sup>74</sup>.

Emotional well-being has also been measured in research with symptoms of depression and anxiety, where lower symptoms were an indicator of better emotional well-being <sup>75-77</sup>. In addition, an emotional well-being subscale in a self-reporting questionnaire has shown significant negative correlations with measures of anxiety and depression <sup>78</sup>. In contrast, anxiety and depression are often referred to as emotional distress. Emotional distress has been defined in, for example, cancer literature as an unpleasant emotional experience, such as anxiety and depression, which might interfere with the ability to cope with the illness <sup>79, 80</sup>. Emotional well-being and emotional distress have been suggested to be inversely related and interact in a dynamic process <sup>81</sup>.

### *2.2.1.2 Emotional well-being in patients with CHF*

Patients with CHF suffer from impaired emotional well-being. The prevalence of emotional distress is higher among patients with CHF compared to healthy elders and to other cardiac patient groups<sup>11</sup>. Reported prevalence of depression ranges from 13 to 77 percent<sup>82</sup>. A recent meta-analysis of the prevalence of anxiety in patients with CHF reported a pooled prevalence of 32 percent, ranging from 6 to 72 percent<sup>83</sup>. Several studies have identified depression as an independent predictor of mortality and readmission to hospital in patients with CHF<sup>18, 84-89</sup>. Depression has also been associated with worse HRQoL<sup>90-92</sup>. Anxiety has been linked to higher readmission rates and lower HRQoL<sup>93, 94</sup>. Furthermore, anxiety and depression predict a decline in physical functioning in patients with CHF<sup>95</sup>. In contrast to these findings, PA has been found to be protective against a 10-year incidence of coronary heart disease<sup>96</sup>. PA has also been associated with reduced inflammatory biomarkers<sup>97</sup> and better self-care management in patients with CHF as well as with perceived positive changes in health behaviour<sup>58</sup>. Low levels of PA have been shown to predict impaired health status in patients with CHF<sup>98</sup>. Despite the detrimental outcomes of impaired emotional well-being in patients with CHF, psychosocial factors are infrequently assessed and treated in clinical practice<sup>99, 100</sup>.

## **2.2.2 Health-related quality of life (HRQoL)**

### *2.2.2.1 Definition*

HRQoL specifies the general concept of QoL from a health perspective, including aspects of physical, psychological and social functioning and is a relating concept to well-being<sup>101</sup>. HRQoL is defined by how health influences the individual's ability to function and the perceived well-being in the physical, psychological and social domains of life<sup>102</sup>.

### *2.2.2.2 HRQoL in patients with CHF*

Individuals with CHF experience poor HRQoL<sup>10, 103</sup>. In addition, HRQoL in patients with CHF is worse compared to age-matched healthy people<sup>104-106</sup>. Poor HRQoL has been found to predict mortality and rehospitalization in patients with CHF<sup>23</sup>. Several studies have found impaired physical functioning, as measured by

NYHA class, to be associated with worse HRQoL<sup>28, 107, 108</sup>. Younger age has also been linked to worse HRQoL<sup>28, 108, 109</sup> and one study found that older patients had better HRQoL than younger patients despite higher NYHA class. However, older patients were at higher risk of worsening HRQoL as a result of deterioration in physical functioning<sup>110</sup>. Patients younger than 65 years were concerned about loss of role and activities and it has been suggested that older people might have altered their expectations<sup>109</sup>. Women have reported worse physical functioning in HRQoL than men<sup>107, 111</sup>. Psychosocial factors, such as greater social support, have been shown to be associated with better HRQoL when controlled for age, gender and NYHA class<sup>112</sup>. Furthermore, when controlled for disease severity, depression has been found to influence HRQoL<sup>113</sup>. One study demonstrated that many patients experience an improvement in HRQoL one month after being hospitalized for heart failure and those patients who didn't experience an improvement were at higher risk of rehospitalization and mortality even when risk factors were controlled for<sup>114</sup>.

## **2.2.3 Coping**

### *2.2.3.1 Theory of stress and coping*

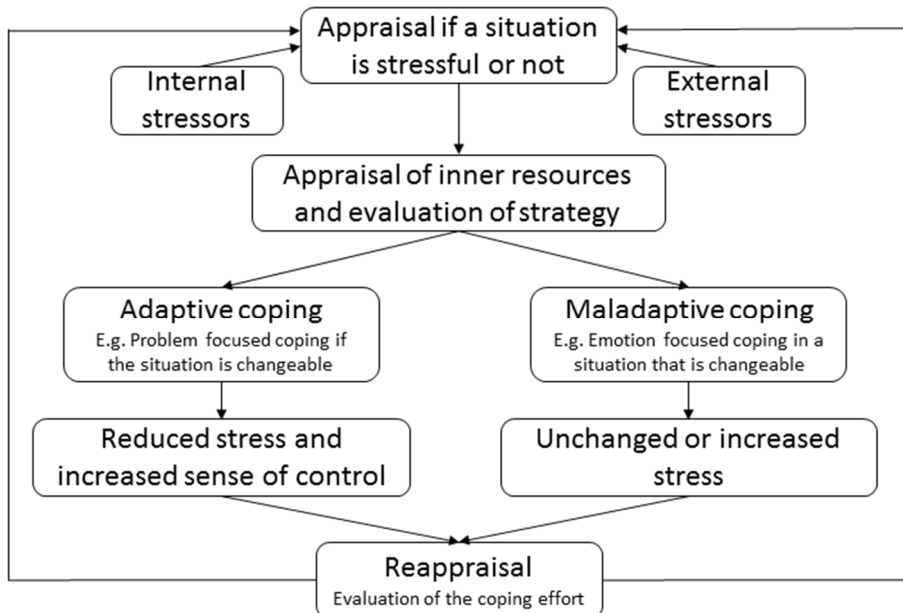
Lazarus and Folkman's cognitive transactional theory of stress and coping provides a framework for the process of coping with stressful situations. Coping is defined as *"constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person"*<sup>115</sup>. According to Lazarus and Folkman there are two main functions of coping: managing or altering the problem causing the distress (problem focused coping) or regulating the emotional response to the stressful situation (emotion focused coping)<sup>115</sup>. How the individual cognitively appraises the situation is also important in the coping process. In a primary appraisal the situation is assessed as being stressful or not and in a secondary appraisal there is a judgment of what might and can be done. In a reappraisal the outcomes of the coping strategy are evaluated, based on new information after a coping effort, and may result in a changed appraisal. The cognitive appraisal processes are usually implicit. That is, the appraisals are automatic rather than based on rational reasoning<sup>115</sup>. The coping strategies can be regarded as either adaptive or maladaptive, depending on whether



the coping strategy chosen is suitable for the situation. Adaptive coping occurs when the coping strategy fits the changeability or controllability of the situation. If the situation is changeable or controllable problem focused coping is most appropriate, while if the situation is unchangeable or uncontrollable emotion focused coping is most suitable. In contrast, maladaptive coping occurs when emotion focused coping is employed in a changeable situation and problem focused coping in an unchangeable situation<sup>116, 117</sup>. Maladaptive coping results in emotional distress<sup>118</sup>. A thematic overview of the theory is displayed in Figure 2.

Derivatives of Lazarus and Folkman's theory of stress and coping occur. Carver, Scheier and Weintraub have, in their development of a self-assessment questionnaire for coping strategies, separated coping strategies generally viewed as maladaptive, such as denial and behavioural disengagement, from emotion focused coping<sup>119</sup>, which Lazarus and Folkman conceptually included in emotion focused coping<sup>115</sup>.

Figure 2. Thematic overview of Lazarus and Folkman's theory on stress and coping.



### 2.2.3.2 *Dispositional coping*

Lazarus and Folkman's theory of stress and coping focus on situational coping where coping strategies change through different stages of the stressful transaction<sup>120</sup>. The other way of modelling coping strategies is through the concept of dispositional coping which, in contrast to situational coping, is a rather stable pattern of coping strategies across different situations. That means that the individual has acquired a habitual way of coping with stress, which in turn can affect how the individual reacts to new situations<sup>121</sup>. In line with the dispositional way of modelling coping strategies, dispositional modelling of appraisal has also been suggested. That is, the individual is predisposed to consistently appraising a stressor as, for example, challenging or threatening. An individual could thereby be either more resistant or vulnerable in stressful situations<sup>122</sup>.

### 2.2.3.3 *Coping with chronic illness*

Moos and Holahan proposed a framework for coping with chronic illness which is, in part, based on crisis theory<sup>123</sup>. In crisis theory the focus is on how the individual manages major life crises. Chronic illness, such as CHF, causes an unbalance and the individual tries to establish equilibrium. The new balance can be achieved either through adaptive coping or maladaptive coping, which will have different consequences for health. The coping process is also believed to be influenced by: personal resources, cognitive appraisal, social and physical context and health-related factors such as illness severity and symptoms<sup>123</sup>.

### 2.2.3.4 *Coping in patients with CHF*

An individual living with CHF needs to cope with the symptom burden of the illness in all dimensions of his or her life and make life style adjustments<sup>8,33</sup>. The patients also need to cope with the uncertain nature of CHF<sup>124</sup>. The importance of coping for health outcomes in patients with CHF has received increasing attention in research<sup>125</sup>. Studies have shown that individuals with CHF who employ problem solving coping strategies, such as planning and taking an active approach to solve a problem, have fewer depressive symptoms<sup>126</sup>, better subjective well-being<sup>127</sup>, less fatigue and more vigour<sup>128</sup>. Active coping in combination with acceptance has been

found to predict fewer physical symptoms<sup>129</sup>. In contrast to these findings another study found approach coping, which included active coping, positive reframing, planning, acceptance, seeking emotional support and seeking instrumental support, not to be associated with physical functioning in patients with CHF<sup>130</sup>. Emotion focused coping, such as acceptance, positive reframing and religious coping have, in a study in the USA, been linked with an increased sense of meaning of life<sup>131</sup>.

Avoidant coping, such as denial and behavioural disengagement, has on the other hand, been associated with increased depression, anxiety and fatigue, worse HRQoL and physical functioning as well as increased mortality<sup>14, 126, 128, 130, 132, 133</sup>. In addition, a literature review has suggested avoidant coping to be negatively associated with adaptive self-care in patients with CHF<sup>134</sup>.

Patients with CHF also use social support to help them adapt to their new life situation, but social support could also be unhelpful in situations where there is excessive help, too much information or criticism<sup>135</sup>.

Few studies have examined the influence of age, gender and NYHA class on coping strategies in patients with CHF. One study, using narratives from semi-structured interviews, found avoidance coping and acceptance to be more salient in patients aged over 70 years. Avoidance was also more salient in patients with moderate to severe limitation in physical functioning<sup>136</sup>. In contrast, another study found that patients with CHF who experienced more physical symptoms tended to use more symptom focused coping, such as resting or taking medication<sup>129</sup>. Gender differences in coping strategies in patients with CHF have been elucidated in a study where men used more emotion focused and avoidant coping strategies, whereas women used optimistic coping strategies and were more hopeful about the future<sup>137</sup>.

#### *2.2.3.5 Measuring coping strategies in patients with CHF*

There is a wide range of self-assessment questionnaires used in research to measure coping strategies in patients with CHF<sup>14, 126, 128, 130, 132, 138, 139</sup>. Among these self-assessments questionnaires are: Dealing with illness-R checklist<sup>140</sup>, Coping Inventory for Stressful Situations (CISS)<sup>141</sup>, Ways of Coping Questionnaire (WCQ)

<sup>142</sup>, Side Effect Coping Questionnaire (SECOPE) <sup>143</sup>, Coping Orientation to Problems Experienced (COPE) <sup>119</sup> and Brief COPE <sup>144</sup>. However, most of the studies have used COPE or Brief COPE when measuring coping strategies in patients with CHF <sup>125</sup>. The 28-item Brief COPE is a shorter version of the 60-item COPE, which reduces the respondent burden <sup>119, 144</sup>. However, there are still many subscales in Brief COPE (14 subscales) which could cause some practical as well as conceptual problems when measuring coping strategies such as: several analyses, fragmentation of results and overlapping coping strategies. In order to solve these problems the subscales of Brief COPE have been modelled into higher order structures, consisting of fewer factors of coping in the context of CHF <sup>127, 130, 145, 146</sup>. However, there is no consensus about the theoretical or empirical foundations of how to group the subscales of Brief COPE in to a higher structure.

## **2.2.4 Illness perception**

### *2.2.4.1 Common sense model of self-regulation*

When a person is faced with an illness or health threat he or she begins to have thoughts, ideas and emotions in the form of so called representations about their illness in order to make sense of the illness. These illness perceptions can vary from person to person <sup>147</sup>. An influential theoretical framework for illness perception is the Common Sense Model (CSM) of self-regulation <sup>148</sup>. The CSM proposes that stimuli, such as symptoms from the illness, give rise to both cognitive and emotional representations in parallel. Coping strategies are then applied to cope with the different representations that have arisen. The efficacy of these strategies are then appraised by the individual and incorporated into their representations. For example, a symptom can give rise to representation of danger (cognitive) and fear (emotional). The individual takes action in order to control the danger, e.g. by giving up smoking <sup>149</sup>.

In the CSM model the cognitive representation consists of five components: identity, timeline, consequences, cause and control. Identity deals with the symptoms the person ascribes the illness. Timeline is the perceived duration of the illness. Consequences are the beliefs about the impact of the illness in one's life.

Cause represents the personal ideas about the causes of the illness. Control is the belief of how manageable the illness is by personal effort or treatment <sup>149</sup>.

#### 2.2.4.2 *Illness perception in patients with CHF*

Several studies have examined illness perception in patients with CHF <sup>150-158</sup>. Illness perception has been shown to be of importance for emotional well-being <sup>153, 156</sup>, HRQoL <sup>157</sup>, self-care behaviour <sup>152, 155</sup> as well as readmission to hospital <sup>158</sup>.

However, only one of these studies examined the association of illness perception with coping strategies and emotional distress, where beliefs about greater consequences of the illness and less personal control were associated with maladaptive coping strategies and greater emotional distress <sup>153</sup>.

### 2.2.5 **Sense of coherence**

#### 2.2.5.1 *Definition and salutogenic theory*

Antonovsky defined the concept of sense of coherence (SOC) as “*a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that one's internal and external environments are predictable and that there is a high probability that things will work out as well as can reasonably be expected*” <sup>159</sup>. SOC is suggested to consist of three parts; meaningfulness, comprehensibility, and manageability <sup>160</sup>. In the salutogenic theory, where the concept of SOC originates from, the focus is on resources that promote health rather than risk factors for illness (pathogenic) <sup>161</sup>. Theoretically, SOC is regarded as an internal resource to cope with stressful situations in life <sup>162</sup>. The salutogenic theory suggests that an individual is never entirely ill or entirely healthy, but is moving in a continuum between the two poles of illness and health <sup>159</sup>.

#### 2.2.5.2 *Sense of coherence in patients with CHF*

Studies regarding the level of SOC in patients with CHF have shown inconclusive results. Two studies found high levels of SOC in patients with CHF <sup>163</sup> even though they had low HRQoL <sup>104</sup>, in contrast to another finding demonstrating low levels of SOC in patients aged over 85 years <sup>164</sup>. High levels of SOC have been indicated to

be associated with better self-management of CHF <sup>165</sup>, more coping resources <sup>163</sup>, and more satisfying social relationships <sup>166</sup> whereas low levels of SOC have been linked to greater mental fatigue such as less ability to concentrate <sup>167</sup>.

## **2.3 INTERVENTIONS TO IMPROVE EMOTIONAL WELL-BEING**

There are many randomized controlled trials (RCT) that have examined interventions with self-care management in patients with CHF <sup>168</sup>, however, the focus of the education has been mainly on physical aspects of self-care and symptom monitoring rather than focusing on behaviour, skills and psychosocial factors. The RCTs that have been conducted with psychoeducational interventions in patients with CHF are few and some of the studies are pilot studies with a small sample size (n=20 and n=43), yet there were still some positive results found such as improved mood state and increased sense of control <sup>169, 170</sup>. Relaxation training for patients with CHF has shown improvements in the psychological, social and spiritual aspects of HRQoL <sup>171, 172</sup>. In a prospective cohort study, with a geographical control group, the intervention consisted of mindfulness training and training in coping skills, resulting in reduced anxiety and depression and improved CHF specific HRQoL <sup>173</sup>. In one RCT study the intervention was partly composed of nurses providing depression care management and an evidence-based problem-solving treatment for depression over the telephone, which resulted in reduced depression and improved problem-solving skills as well as self-efficacy <sup>174</sup>. There are a few studies that have examined self-management programs tailored at behavioural change, or psychosocial self-management skills <sup>175, 176</sup>. Improvements were found in disease specific HRQoL, however, the results were inconclusive with regard to time-duration of the effect. In addition, no effects were found in mental functioning, perceived control, self-efficacy, anxiety and depression <sup>175, 176</sup>.

### 3 RATIONALE

CHF is a serious and chronic syndrome with a poor prognosis and symptom burden comparable to many cancer diagnoses. CHF imposes a high burden on the health-care system and caregivers. Patients with CHF experience impaired HRQoL and there is a high prevalence of anxiety and depression. Many studies have shown adverse outcomes on poor HRQoL as well as anxiety and depression for patients with CHF, such as increased mortality and readmission to hospital. Despite these detrimental outcomes elucidated in research, the psychosocial aspects of patients with CHF are seldom cared for and treated. There is a lack of evidence on how psychosocial support and training of psychosocial self-care skills could be provided in a systematic manner. The research conducted on self-care management programs has focused mainly on the physical aspects of self-care management in patients with CHF. Coping and illness perception are important factors for an individual with CHF to adjust to his or her life situation and for emotional well-being. Therefore, in order to improve emotional well-being in patients with CHF, interventions should focus on coping skills and the appraisal of the illness. Coping effectiveness training intervention could provide such an approach.

Since research has highlighted the importance of coping to health outcomes in patients with CHF, it is essential to have a reliable and valid measurement model of coping strategies that is feasible to use in research as well as in clinical practice.

Little is known about the pattern and pathways between illness perception, coping strategies and emotional well-being in patients with CHF. There is a need to better understand these mechanisms in order to identify variables that might be of importance in a psychosocial intervention. Furthermore, research on factors that might influence the choice of coping strategies, such as illness severity, demographic variables as well as sense of coherence, in patients with CHF is limited and requires further investigation. There is also limited knowledge of how different coping strategies influence positive as well as negative affect considered as a main pillar of emotional well-being.

## 4 AIMS OF THE THESIS

### 4.1 OVERALL AIM

To gather scientific evidence regarding the influence of illness perception, coping strategies and sense of coherence on emotional well-being in patients with CHF. Furthermore, to establish a theoretically and empirically sound measurement model of coping strategies. Finally, to develop, implement and evaluate a nurse-led psychoeducational intervention for improving patients' adaptive coping skills, appraisal of the illness, emotional well-being, HRQoL and clinical outcomes.

### 4.2 SPECIFIC AIMS

The specific aims of each study were to:

Investigate whether functional status, demographic variables and sense of coherence may be related to the coping strategies used by patients with CHF, and to examine how coping strategies may be associated with different dimensions of affect, considered as a main pillar of emotional well-being for these patients. **(I)**

Examine the structure of Brief COPE, founded on the higher order grouping of its subscales, in order to establish an assessment model supported by theoretical considerations. Furthermore, to examine the associations between these higher order categories of coping and HRQoL in order to establish the predictive validity of the selected model in the context of CHF. **(II)**

Examine the links between illness perceptions, coping style and anxiety and depression, and to examine the potential mediating role of avoidant coping style and illness perception on these links in patients with CHF. **(III)**

Develop, implement and evaluate a Coping Effectiveness Training (CET) program for patients with CHF, with the objective of increasing emotional well-being (primary outcome), HRQoL (secondary outcome) and improve clinical outcomes (tertiary outcome). Furthermore, the study also aimed to examine changes in appraisal of illness burden and control over the illness as well as coping styles as potential mediators of the intervention effect. **(IV)**



## 5 METHODS

### 5.1 STUDY DESIGN

In this thesis a wide range of quantitative methodologies were applied. A cross-sectional research design was applied in Studies I-III. Study I examined correlations and predictions. Study II was a methodological study and Study III tested models of mediational relations. In study IV a randomized controlled longitudinal research design was carried out in order to evaluate CET intervention in patients with CHF.

Table 2. Overview of Studies I-IV

	<b>Study I</b>	<b>Study II</b>	<b>Study III</b>	<b>Study IV</b>
<b><i>Design</i></b>	Cross-sectional research design	Methodological cross-sectional research design	Cross-sectional research design	Randomized controlled trial
<b><i>Self-assessment questionnaires</i></b>	Brief COPE PANAS <sup>a</sup> SOC <sup>b</sup> -scale	Brief COPE RAND-36 <sup>c</sup>	B-IPQ <sup>d</sup> Brief COPE HADS <sup>e</sup>	B-IPQ Brief COPE ESSI <sup>f</sup> HADS PANAS RAND-36
<b><i>Clinical &amp; demographic measurements</i></b>	Age NYHA class Sex	Age Duration of CHF NYHA class	NYHA - class	Readmission to hospital Mortality Age Sex
<b><i>Sample</i></b>	n = 80	n = 183	n = 103	n = 103

<sup>a</sup> Positive Affect Negative Affect Schedule, <sup>b</sup> Sense of Coherence, <sup>c</sup> Research And Development 36-item health survey, <sup>d</sup> Brief Illness Perception Questionnaire, <sup>e</sup> Hospital Anxiety and Depression Scale, <sup>f</sup> ENRICHD Social Support Inventory

## **5.2 STUDY SAMPLE AND SETTING**

### **5.2.1 Study I**

Participants were enrolled in the study at a heart failure ward and at a nurse-led heart failure outpatient clinic at a hospital in Stockholm County Council, Sweden. Enrolled patients met the following inclusion criteria: NYHA class II-IV and aged over 18 years. The exclusion criteria were: cognitive dysfunction, life threatening disease such as cancer or primary organ failure and not being able to understand the Swedish language. In total 143 patients were asked by the research nurse to participate in the study and 94 accepted to join. Fourteen participants were excluded owing to an incomplete response or no response at all. Consequently, 80 participants were included in Study I.

### **5.2.2 Study II-IV**

Participants were included from a waiting list at a nurse-led heart failure outpatient clinic at a hospital in Stockholm County Council, Sweden. The following inclusion criteria were applied: classified as NYHA class II-III and aged over 18 years. The exclusion criteria were: cognitive dysfunction, a life threatening disease such as cancer or primary organ failure and/or a severe psychiatric diagnosis such as psychosis or severe depression, and not being able to understand the Swedish language. A total of 103 patients accepted to join the study. In Study II the study sample was merged with the sample in Study I ( $n = 80$ ) hence a total of 183 participants were included in Study II. In Study III and Study IV the study sample consisted of 103 participants.

## **5.3 PROCEDURE**

### **5.3.1 Study I-III**

The participants filled in self-assessment questionnaires at one time point after accepting to join the studies (I-III). In Study I the participants could choose to fill in the self-assessment questionnaires at the hospital or at home. Pre-stamped, addressed envelopes were handed out together with the questionnaires. Reminders

were sent out to the participants after two and four weeks in Study I and after one and two weeks in Studies II-III.

### **5.3.2 Study IV**

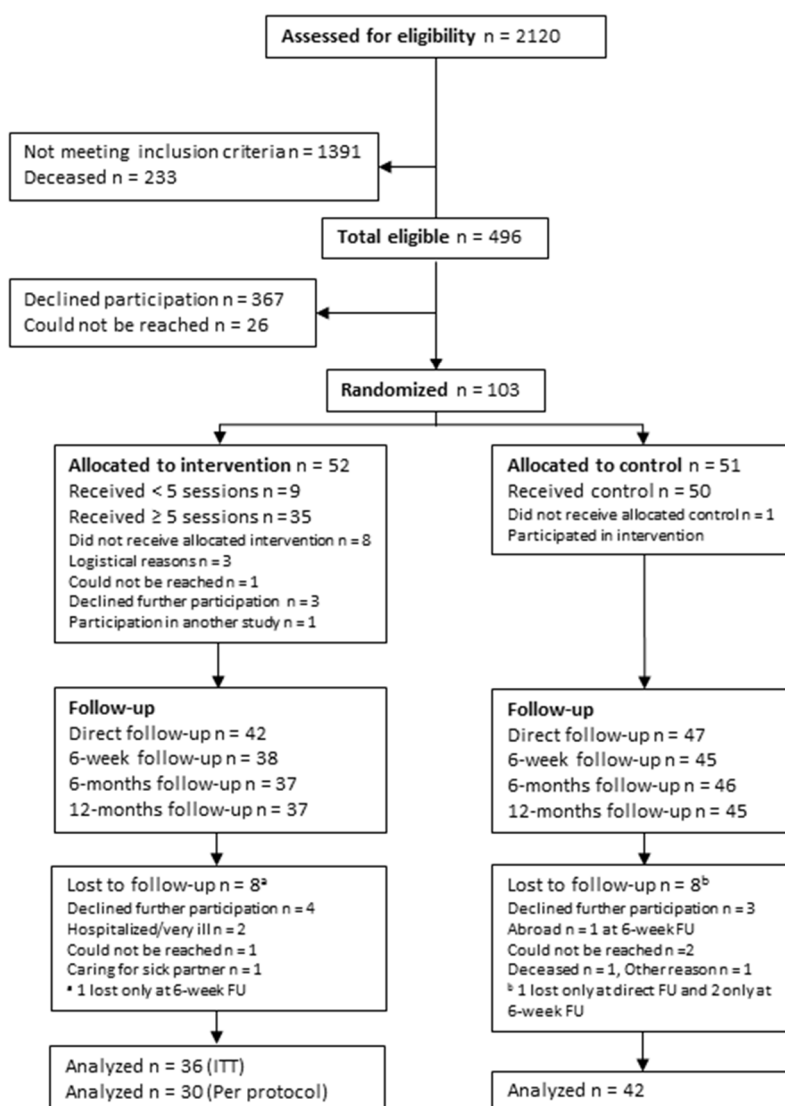
Random allocation sequences were generated in Excel® (Microsoft, Redmond, WA, USA) in blocks of 30 by the principal supervisor. The author and the principal supervisor prepared sealed envelopes containing a paper stating the allocated randomization group. Afterwards the envelopes were randomly mixed and a number according to the random number sequence was written on the envelope.

Eligible patients were either informed verbally, and given written information at the outpatient clinic, or were sent written information by post to their home with a follow-up telephone call one week later to provide verbal information. After accepting to join the study the participants were given self-assessment questionnaires that they filled in at home and returned by post. The number on the self-assessment questionnaires was noted with the participant's social security number and name. The participants were enrolled mainly by the author and some by colleagues at the nurse-led heart failure outpatient clinic. The colleagues had received both written and oral information about the study procedure. After the baseline measurement was completed and returned, the author opened the sealed envelope corresponding to the number on the baseline measurement and the participants were randomized in to one of two arms; control group (CG) or intervention group (IG). Specific information about allocation to randomization groups was posted to the participants' homes.

The self-assessment questionnaires were sent out again by post at: post-intervention, six weeks, six months and twelve months after the intervention to both randomization groups. Reminders were sent after one and two weeks, and after three weeks a phone call was made to those who had not yet returned the questionnaires. In addition, an anonymous written evaluation form was filled in by the participants in the IG directly after finishing the CET. The enrolment and flow of study participants throughout Study IV are displayed in Figure 3. The enrolment

process took two and a half years between 2010 and 2013. The trial has been registered at ClinicalTrials.gov: NCT02463903.

Figure 3. Flow chart of screening, enrolment, randomization and follow-up of participants in Study IV. The randomized participants,  $n = 103$ , were included in Study II and Study III. Number of people analysed in Study IV is stated for the Repeated measures ANCOVA. In the survival analysis  $n = 44$  in the intervention group and  $n = 50$  in the control group were analysed. (The figure is from Paper IV in this thesis.)



#### *5.3.2.1 Control group*

The participants in the CG received standard health care for patients with CHF such as: nurse-led heart failure outpatient clinic, cardiology specialist outpatient or primary health care.

#### *5.3.2.2 Intervention group*

Apart from standard health care the participants in the IG also received CET, a manual-based group intervention. The CET intervention is based on Lazarus and Folkman's theory of stress and coping<sup>115</sup>. CET has previously been applied to other patient groups with serious chronic conditions, such as HIV and spinal cord injury (SCI), and showed positive results<sup>177, 178</sup>. The purpose of the CET was to improve participants' skills to appraise stress, to teach a number of techniques to cope with stress, and to provide an opportunity to interact with other people living with CHF. The participants received seven 90 minute CET sessions weekly and a workbook with a brief summary and goals of every session, as well as home assignments. Table 3 displays the theme for each session. The groups were led by the author of this thesis, a cardiac nurse specialized in CHF with more than 10 years experience, who received supervision by a psychologist the fifth author in Study IV. The first group was jointly led by the nurse and the psychologist and subsequent groups by the nurse alone. After each CET session the nurse received supervision from the psychologist. In total there were five intervention groups with 7-12 people in each group. The sessions were held in a conference room at the author's institution. Both the workbook and the manual were translated from English in to Swedish and adapted for patients with CHF from Kennedy's original books applying CET for patients with SCI<sup>179, 180</sup>, by the author of this thesis and the fifth author in Study IV.

Table 3. Themes for each CET session.

Session	Theme
1	Introduce the concept of stress and coping. Identify individual stress reactions.
2	Identify stress evoking appraisals. Introduce coping strategies. Break down stressful situations into manageable parts.
3	Explain problem focused coping. Practice a structured problem solving method.
4	Explain emotion focused coping. Practice relaxation training. Scheduling positive activities to counteract negative thoughts.
5	Challenging negative thoughts. Discuss negative automatic thinking and common thinking errors.
6	Discuss adaptive and maladaptive coping and identify such personal coping strategies.
7	Present different kinds of social support and discuss how social support can reduce stress, facilitate problem solving and generate positive emotions.

## 5.4 DATA COLLECTION

### 5.4.1 Demographic and clinical data

In all the studies, demographic data were filled in by the participants on a form together with the self-assessment questionnaires that were handed out after they had accepted to participate. Clinical background data were gathered via the participants' medical journals by the author of this thesis. In Study IV clinical outcome measurements of rehospitalization and death as well as total time for inpatient care were obtained from a central regional database at the Stockholm County Council. Time to death and hospitalizations cardiovascular cause and all cause were measured during the entire follow-up period (median 35 months, IQR 11 months).

## 5.4.2 Self-assessment questionnaires

### 5.4.2.1 Brief COPE (Study I-IV)

To measure coping strategies Brief COPE was utilized<sup>144</sup>. Brief COPE is a shorter version of the 60-items COPE inventory<sup>119</sup> thus relieving some of the respondent burden. Brief COPE has 28 items and measures 14 coping strategies: *Active Coping, Planning, Positive Reframing, Acceptance, Humour, Religion, Using Emotional Support, Using Instrumental Support, Self-Distraction, Denial, Venting, Substance Use, Behavioural Disengagement, and Self-Blame*. Each coping strategy is indicated by two items. The respondent is asked to think about the following: What do you usually do when you are stressed by a problem? The 28 items consist of statements such as “I try to come up with a strategy about what to do”. Each statement is graded on a 4-point Likert scale: 1 = Very seldom, 2 = Fairly seldom, 3 = Fairly often, 4 = Very often. Higher sum score of each subscale indicate greater utilization of the coping strategy. Brief COPE has proven to be a reliable and valid measurement of coping styles and has been used in research with a heart failure population showing good internal consistency<sup>130</sup>. The Swedish version of Brief COPE has been psychometrically tested and proved to have adequate properties<sup>181</sup>.

### 5.4.2.2 Brief Illness Perception Questionnaire (B-IPQ) (Study III, IV)

B-IPQ measures illness perception and consists of nine items<sup>182</sup>. B-IPQ was developed from the 80-item IPQ<sup>147</sup> and IPQ-R<sup>183</sup>. The short form was used because it could be more suitable for severely ill or elderly people, as it reduces respondent burden. Of the nine items, eight new items were developed to mirror each subscale in IPQ-R, one item summarising each subscale<sup>182</sup>. Five items assess cognitive representations; *consequences, timeline, personal control, treatment control and identity*. One item assesses *illness comprehensibility*. Two items assess emotional representations: *concern* and *emotions*. The last item is an open ended question and assesses casual representation by asking the respondent to list three reasons that could have caused the illness. Each subscale is indicated by one item. The rating scale of the first eight items ranges from 0 to 10 on a unipolar scale with verbal labels on each side of the scale. Higher scores indicate a more threatening view of the illness, except for the two items that measure control where higher

scores indicate greater control. The psychometric properties of B-IPQ have been tested in several patient groups, including cardiac patients and have shown good reliability and validity <sup>182</sup>. Previous research has used B-IPQ in patients with CHF <sup>154</sup>.

#### 5.4.2.3 *ENRICHD Social Support Inventory (ESSI) (Study IV)*

ESSI was developed for the Enhancing Recovery in Coronary Heart Disease Patients (ENRICHD) trial <sup>184</sup>. ESSI consists of seven self-assessed items where the first six items measure four components of social support: emotional, instrumental, informational and appraisal support <sup>185</sup>. The items in ESSI derive from items from other social support instruments that have been found to be individually predictive of death in cardiac patients <sup>184</sup>. These items are represented by statements such as: “Is there someone available to you who shows you love and affection?” and are rated on a five point Likert scale rating from *never* to *always*. The seventh item concerns marital status. A higher total sum score indicates greater social support. ESSI has been validated in cardiac patients <sup>185, 186</sup>. ESSI has, within the current doctoral project, been translated to Swedish, using forward and backward translation, expert group and cognitive interviewing with think-aloud protocol <sup>187</sup>.

#### 5.4.2.4 *Hospital Anxiety and Depression Scale (HADS) (Study III, IV)*

HADS is a 14-item questionnaire that measures anxiety and depression <sup>188</sup>. Seven items represent anxiety and seven items represent depression. Each item has four answers to choose from and the answers are scored from 0-3. The subscales of anxiety and depression can have scores ranging from 0-21 where a higher score indicates greater anxiety and depression. A cut-off point of  $\geq 11$  has been suggested for definitive clinical cases of anxiety and depression <sup>188</sup>. HADS was intended for medically ill patients and does not take clinical symptoms of anxiety and depression, such as heart palpitation and fatigue, into account as these symptoms might also indicate a medical condition <sup>188</sup>. The Swedish version of HADS has been psychometrically tested and proven to be a reliable and valid clinical indicator for anxiety and depression <sup>189</sup>. HADS has been used in heart failure populations,



showing good reliability and prognostic value<sup>87, 130</sup> and is well-established in cardiac patients<sup>190</sup>.

#### 5.4.2.5 *Positive Affect Negative Affect Schedule (PANAS) (Study I, IV)*

PA and NA are measured with the 20-item PANAS<sup>73</sup>, which is a self-assessment questionnaire consisting of 20 adjectives describing different emotions. Ten items assess PA e.g. interested, enthusiastic and alert, and 10 items assess NA e.g. ashamed, hostile and upset. The main question was; “Please state to what extent you have felt this during the past four weeks.” The items are rated on a 5-point Likert scale: 1 = not at all, 2 = a little, 3 = moderately, 4 = quite a bit, 5 = very much. Higher sum scores on the two subscales indicate greater PA and NA. The reliability and validity of PANAS has been tested and found to have good psychometrical properties<sup>73, 191</sup>. PANAS has demonstrated good internal consistency in research involving patients with CHF<sup>58, 192</sup>.

#### 5.4.2.6 *RAND 36-item Health Survey 1.0 (Study II, IV)*

The RAND 36-item Health Survey 1.0 is a generic profile, self-reported instrument of HRQoL and includes eight subscales; *physical functioning, role limitation due to physical health, role limitation due to emotional problems, energy/fatigue, emotional well-being, social functioning, bodily pain and general health*. A single item also measures perceived change in health during the past year<sup>193</sup>. The items are identical to the ones in the Medical Outcomes Study (MOS) 36-item short form health survey (SF-36)<sup>194</sup> but the scoring is somewhat different. Scoring is done by recoding the items between 0 and 100, where a higher score indicates a better health condition. The items are averaged to create each scale and missing data are not taken into account, so the average represents the items actually responded to in each scale. RAND 36 has also been suggested to consist of two health summary scores; a physical and a mental health composite. The physical health composite derives from the subscales: physical functioning, role limitation due to physical health, bodily pain and general health. The mental health composite derives from the subscales: role limitation due to emotional problems, emotional well-being, social functioning and energy/fatigue<sup>195</sup>. RAND 36 has shown good psychometric

properties <sup>196</sup> and has been used in many studies for measuring HRQoL in patients with CHF <sup>197-199</sup>.

#### 5.4.2.7 *Sense of Coherence (SOC)-scale (Study I)*

For assessing SOC the shorter 13-item SOC-scale was used, which originates from the 29-item SOC-scale <sup>200</sup>. The SOC-scale measures three components of SOC: comprehensibility, manageability and meaningfulness. Each item is rated on a unipolar scale ranging from 1-7 with two anchoring responses e.g. never and very often. An item can be phrased like; “How often do you have the feeling that there’s little meaning in the things you do in your daily life?” Some item scores are reversed before the total sum score can be calculated. The possible total score ranges from 13 to 91 where a higher score indicates a stronger sense of coherence. The SOC-scale has been proved to possess good psychometrical properties worldwide <sup>201</sup>. The Swedish version of the 13-item SOC-scale has been found to be reliable and valid <sup>202</sup> and has been utilized to measure SOC in individuals with CHF in Sweden <sup>167</sup>.

## 5.5 DATA ANALYSIS

A summary of the data analysis is given in this section. Studies I and IV used general linear models (GLM) <sup>203</sup> and Studies II and III used structure equation modelling (SEM) <sup>204</sup> in the main analysis. Detailed descriptions of the statistical analyses performed in the studies can be found in each individual Study paper.

Table 4. Overview of the statistical analyses employed in each study.

<b>Study I</b>	<b>Study II</b>	<b>Study III</b>	<b>Study IV</b>
Student’s t-test. Mann-Whitney U-test. Pearson and Spearman correlation analysis. Multiple linear regression analysis.	Confirmatory Factor Analysis. Pearson correlation analysis. Hierarchical linear regression analysis.	Path-analysis. Mediation analysis. Pearson correlation analysis.	Chi-square test. Fisher’s exact test. Student’s t-test. Repeated Measures and Mixed ANCOVA. Univariate ANOVA. Kaplan-Meier. Cox regression. Mann-Whitney U-test.

### 5.5.1 Study I

Statistical analyses were carried out with the statistical software IBM Statistical Package for Social Sciences (SPSS) Statistics version 16 for Windows (SPSS inc, Chicago, IL, USA). Differences in the choice of coping strategies between NYHA classes II and III and gender groups were analysed with Student's t-test for normally distributed data or Mann-Whitney *U*-test for variables departing from normality (religion and substance use). For the purpose of examining the associations between age and SOC with coping strategies Pearson correlation and the non-parametric Spearman correlation analyses were performed. Furthermore, in order to examine the associations between SOC and higher order grouping of coping strategies with PA and NA, correlation analyses were carried out. Variables that showed significant correlations with PA and/or NA in the latter analyses were included in regression analyses with the aim of examining the predictive value for PA and NA.

### 5.5.2 Study II

IBM SPSS Statistics version 22, SPSS Amos version 22 (IBM corp. Armonk, NY, USA) and Mplus version 7.1 (Muthén & Muthén, Los Angeles, CA, USA) were used to perform the statistical analyses in Study II. In order to evaluate different proposed higher structure models of Brief COPE, Confirmatory Factor Analyses (CFA) with maximum likelihood estimation were performed. The following model fit indices were applied: Chi-square test statistics, Comparative Fit Index (CFI), Root Mean Squared Error of Approximation (RMSEA) and Standardized Root Mean square Residual (SRMR). For comparison between nested models the likelihood ratio test (LRT,  $\Delta\chi^2$ )<sup>205</sup> was utilized. For examining theoretically justifiable modifications to improve fit of acceptable models, Modification Indices (MI) were inspected. The following six models of Brief COPE were included in CFA: two 2-factor models<sup>130, 145</sup>, one 3-factor model<sup>146</sup> and three 4-factor models where one of the models was from Study I<sup>119, 206, 207</sup>.

The predictive validity of the best fitted higher order structure of Brief COPE was investigated with hierarchical linear regression analysis, with measures of physical and mental health composites in the RAND 36-item Health Survey 1.0<sup>193</sup> as dependent variables. In the first block age, NYHA class and duration of CHF (dichotomized in  $<$  or  $\geq$  6 months) were entered and in the second block the higher order categories of coping strategies in Brief COPE were entered, together with the significant predictors in the first block as independent variables.

### **5.5.3 Study III**

Statistical analyses were performed with IBM SPSS Statistics version 22, SPSS Amos version 22 and Mplus version 7.2. The mediation analyses were founded on Baron and Kenny's<sup>208</sup> and MacKinnon's<sup>209</sup> recommendations on steps in mediation analysis, and were extended to include multiple mediators. The hypothesized mediation models were constructed based primarily on two different theoretical assumptions; the theory of self-regulation<sup>148</sup> and the theory of dispositional coping<sup>121</sup>. If a hypothesized mediator, either domains of illness perception or avoidant coping, could not be regressed on a predictor, and/or if the outcomes could not be regressed on the mediator, the mediation hypothesis was discarded<sup>208, 209</sup>.

### **5.5.4 Study IV**

Statistical analyses were carried out using IBM SPSS Statistics version 22 (IBM corp. Armonk, NY, USA). A power analysis was calculated based on PANAS with a moderate effect size of Cohen's  $d = 0.50$  and  $\alpha = 0.05$ , indicating that to obtain a power of 0.80 a sample size of 72 patients was required. To account for drop-outs another 15 participants were added to each arm to ensure an adequate sample size.

The primary analysis was performed with intention to treat (ITT) and the secondary analysis with per protocol (PP). Analysis with ITT included participants that attended at least one CET session, as no follow-up data were obtained from those who dropped out before the start of the intervention. In the analysis with PP attending five or more CET sessions was regarded as completing the CET.

The primary and secondary outcomes were analysed with a 2 x 4 mixed design (Intervention x Time) ANCOVA with the baseline assessments of each dependent variable included as a covariate. Follow-up analyses to significant treatment main effects were carried out by univariate ANOVA and effect size was described with Cohen's d. In order to exclude clinical cases of anxiety and depression the analyses were performed amongst cases with a cut-off value on HADS < 11<sup>188</sup>. Finally, the analyses were replicated with adjustment for social support.

To evaluate the tertiary outcome, Kaplan-Meier analyses were performed on time from start of the intervention to cardiovascular and all cause readmission to hospital or death. Hazard ratio (HR) was analysed with Cox regression adjusted for age and sex. Total time for inpatient care was analysed with Mann-Whitney U-test.

## 6 ETHICAL CONSIDERATIONS

Research involving human beings should be conducted in accordance with the international ethical guideline Declaration of Helsinki <sup>210</sup>. The guiding principles highlight, for example, beneficence, protection of vulnerable groups, informed consent and confidentiality which were considered during the whole process of this doctoral research project.

The four studies were approved by the Regional Ethics Review Board at Karolinska Institutet, Stockholm Dnr 2007-1302-31/2 (Study I), Dnr 2010/1867-31/5 and amendment Dnr 2011/1132-32 (Studies II-IV).

All research participants were given verbal and written information about the study before giving their acceptance to participate. The written information explained: the purpose and procedure of the study, assurance of patients' confidentiality, voluntary participation and the right to withdraw from the study at any time without giving a reason. It was made clear that non-participation would not influence the patients' future health care. Contact information for the research group was also given. Eligible patients were given time to consider before deciding to accept or not. Patients with CHF could be considered to be a vulnerable group, therefore, attention was given to signs of doubt so not to apply pressure on patients to participate. The patients who accepted to participate signed an informed consent and were given a copy of the document. For some eligible patients the author of this thesis was also the treating nurse at the heart failure outpatient clinic. However, none of the participants were a patient of the author at the same time as the intervention was being held.

All data were coded and a code list was kept in a secure location in order to ensure confidentiality. The results from the studies were presented on a group level so that no individual identities were revealed.

There was no risk of physical harm to any participants in the studies. Contact information for the researchers was given in case of any questions that might arise when, for example, answering the self-assessment questionnaires that might be experienced as difficult or sensitive to answer. Special consideration was taken to

reduce respondent burden when choosing the self-assessment questionnaires for the studies, which is why some of the self-assessment questionnaires were a shorter version of the original. Answering the questions could be regarded as beneficial, in that it allowed time for reflection by participants.

Potential benefits for the intervention group, participating in Study IV, could be the positive effects of the intervention itself. The participants randomized to the control group might have been disappointed. Clear information was given prior to acceptance to participate that the participants would be randomized. Only one participant randomized to the control group stated that the allocation was the reason for declining further participation in the study. On the other hand, the participants in the control group may still have felt that they were contributing to development, implementation and evaluation of a psychoeducational intervention for patients with CHF.

When the Coping Effectiveness Training groups were formed in Study IV information was given at the start about the rule of confidentiality within the group. That is, experiences and opinions shared in the group during the sessions would stay within the group.

## 7 RESULTS

The results are presented in a logical, rather than chronological, order as follows: factors that might influence coping strategies, a model for measuring coping strategies, the influence of coping strategies on different outcomes in emotional well-being and HRQoL and finally the evaluation from the CET intervention. Clinical and demographic data of the participants can be found in each individual Paper.

### 7.1 LINKS BETWEEN NYHA CLASS, AGE, GENDER AND SOC WITH COPING

The hypothesised association between functional status, NYHA class and coping strategies used by individuals with CHF was not confirmed in Study I. No significant differences between NYHA class II and III were found. The demographic variables, age and gender, included in the hypothesis did not show any significant differences or associations with coping strategies except for one; substance use. Men had a significantly higher mean rank score than women (Mann–Whitney  $U = 428.5$ ,  $p < 0.01$ ) for substance use. Furthermore, there was a negative significant correlation with age for substance use ( $\rho = -0.35$ ,  $p < 0.01$ ). Total score of SOC had significant negative correlations with the coping strategies venting,  $r = -0.35$ ,  $p < 0.01$ , and self-blame,  $r = -0.40$ ,  $p < 0.01$ .

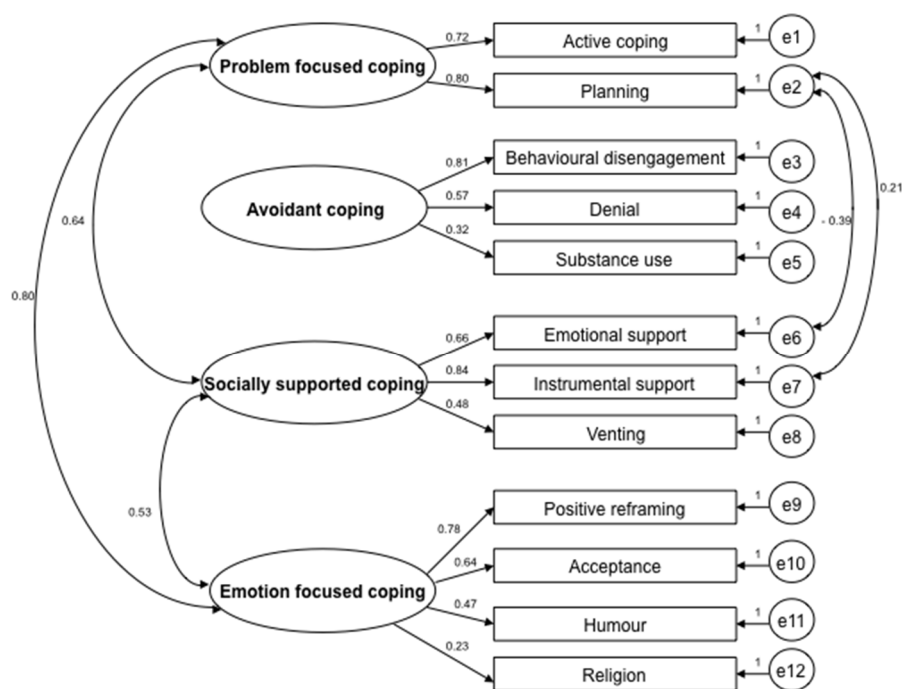
### 7.2 A FOUR-FACTORIAL MODEL FOR MEASURING COPING STRATEGIES

Analyses of the Brief COPE models with CFA in Study II revealed poor model fit indices for the two-factor models and the three-factor model. The four-factorial model of Brief COPE presented by Perez et al.<sup>127</sup> showed improved but not satisfactory model fit statistics. When constructing a model of Brief COPE, based on the original COPE generating a four-factorial structure, acceptable fit statistics were approached with the exception of RMSEA<sup>211</sup>. The four-factorial model of Brief COPE suggested by Nahlén et al.<sup>207</sup> in Study I in this thesis was found to have fairly good model fit indices. Examining MI for the four-factor model proposed in Study I revealed that the model was further improved if the error



variance for planning, emotional support and instrumental support were allowed to co-vary. The improvement of the fit statistics of this model on the basis of these modifications was further supported by the LRT ( $\Delta\chi^2 = 21.24, df = 2; p < 0.001$ ). The model with the different components for each higher order coping factor, is displayed in Figure 4.

Figure 4. The modified four-factor model of Brief COPE that showed the best psychometric properties. (The figure is from Paper II, published in Cardiology Research.)



## 7.3 COPING AND OUTCOMES IN EMOTIONAL WELL-BEING AND HRQOL

### 7.3.1 Positive and negative affect

In Study I, correlations between coping strategies and different dimensions of affect were examined. Active coping, positive reframing, and emotional support correlated significantly with PA ( $p < 0.01$ ). Venting, behavioural disengagement, substance use and self-blame correlated significantly with NA ( $p < 0.01$ ).

Correlations with PA and NA were furthermore explored with the four-factor model of Brief COPE as well as SOC.

The variables that significantly correlated with PA and NA were included as predictors in regression analysis for PA and NA (Table 5). Problem focused coping significantly predicted PA, however, the total variance explained by this regression analysis was limited to 14%. Avoidant coping, socially supported coping and SOC, significantly predicted NA and accounted for 31% of the total variance in this dimension of affect.

Table 5. Regression analysis of Positive Affect (PA) and Negative Affect (NA). Each dimension of affect is a dependent variable regressed separately on its predictors. (The table is from Paper I, permission from the publisher has been retrieved.)

Independent variable	Standardised betas ( $\beta$ )	t
Dependent variable: PA <sup>a</sup>		
Problemfocused coping	.28	2.13*
Socially supported coping	.13	0.96
$r^2 = 0.14$ , $F(2,77) = 6.00$ , $p < 0.01$		
Dependent variable: NA <sup>b</sup>		
Avoidant coping	.26	2.53*
Socially supported coping	.24	2.47*
SOC <sup>c</sup> total	-.32	-3.23**
$r^2 = 0.31$ , $F(3,76) = 11.58$ , $p < 0.001$		

\*  $p < .05$ , \*\*  $p < .01$ , <sup>a</sup> Positive Affect, <sup>b</sup> Negative Affect, <sup>c</sup> Sense of Coherence

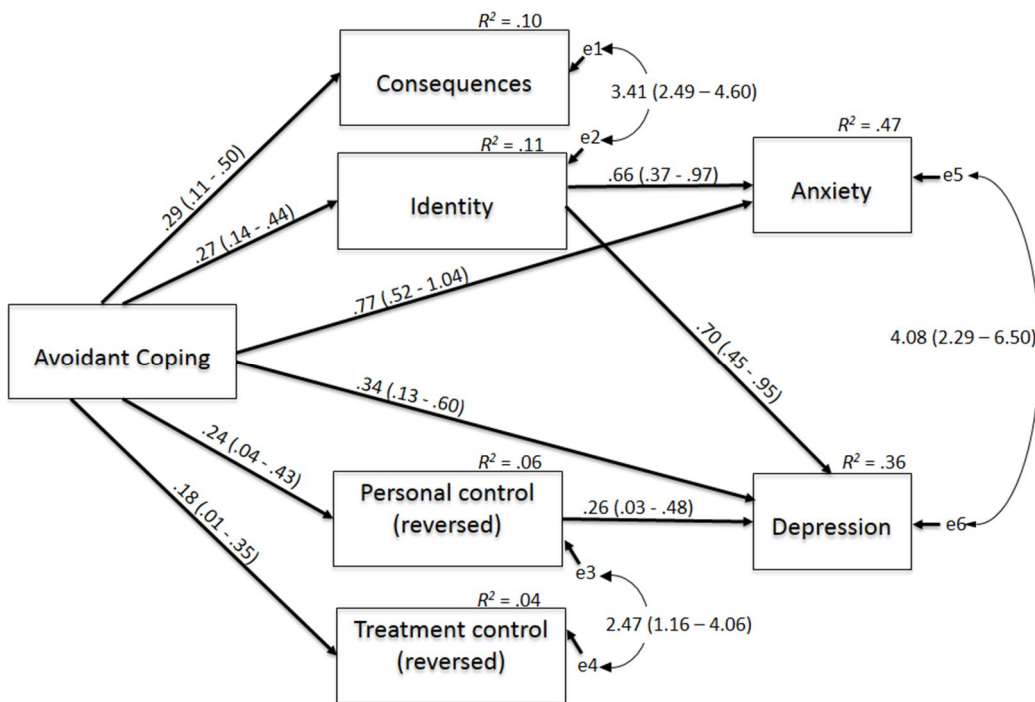
### 7.3.2 Depression and anxiety

In Study III, two hypothesised pathways for coping, illness perception and emotional distress were examined.

The mediation model based on Leventhal's theory could not be confirmed with the data in the study where avoidant coping was a mediator between illness perception and emotional distress. The hypothesised model, where illness perception was a mediator between avoidant coping and anxiety and depression, was found to have good model fit indices ( $\chi^2 = 13.52$ ,  $df = 9$   $p = 0.14$ , CFI = 0.981, RMSEA = 0.072 90 % CI = 0.000 – 0.145, SRMR = 0.047). The influence of Avoidant coping on depression was partly mediated by Identity and Personal control and the influence of Avoidant coping on Anxiety was in part mediated by Identity. This mediation

model explained 47 percent of the variance in Anxiety and 36 percent of the variance in Depression (Figure 5).

Figure 5. Final mediation model with items from B-IPQ as mediators between Avoidant coping and Anxiety and Depression. The illness perception items Personal control and Treatment control are reversed, meaning higher score indicate lower sense of control. The displayed path coefficients are unstandardized (*B*) and the values in brackets display bias corrected 95 % confidence intervals (CI). (The figure is from Paper III in this thesis.)



### 7.3.3 HRQoL

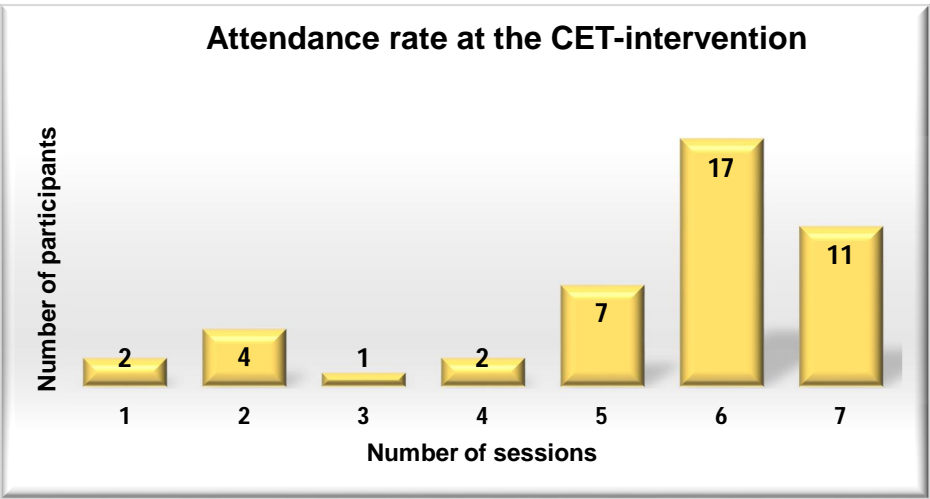
In Study II, the four higher order groupings of coping in Brief COPE were examined as predictors of both the physical and mental composite of RAND 36 in order to establish the predictive validity of the proposed four-factor model. Avoidant coping and NYHA class significantly inversely predicted both physical ( $F(6) = 4.61$ ,  $P < 0.001$ ) and mental aspects ( $F(6) = 11.36$ ,  $P < 0.001$ ) of HRQoL when controlled for age. Problem focused coping, emotion focused coping and socially supported coping did not predict outcomes in HRQoL. The model in the hierarchical multiple regression analysis explained 26 % of the variance of the

physical health composite, and the corresponding explained variance for the mental health composite was 40%.

**7.4 EVALUATION OF A COPING EFFECTIVENESS TRAINING INTERVENTION**

In Study IV, evaluation of the CET intervention was carried out with Patient Reported Outcome Measures (PROM) and clinical outcome measures. Additional results from an evaluation with Patient Reported Experience Measure (PREM) are also presented. There were no statistically significant differences between the baseline characteristics of the two randomization groups or between participants lost to attrition (n = 8) and those who received the intervention (n = 44) and between those who completed the intervention (n = 35) compared to non-completers (n = 9). The attendance rate at the CET intervention was good, where 80 percent attended five or more CET sessions (Figure 6).

Figure 6. The attendance rate of the CET intervention, n = 44. 80 percent attended 5 or more CET-sessions.



**7.4.1 Patient reported outcomes**

The PROMs were PANAS, HADS, RAND 36, B-IPQ, Brief COPE and ESSi.

#### 7.4.1.1 Emotional well-being and HRQoL (primary and secondary outcome)

In the primary outcome, lower average mean scores were shown for NA, anxiety, depression as well as higher average mean scores for PA. In the secondary outcome, higher average mean scores were found for the physical and mental component of RAND 36 for the IG (Table 6). However, these average mean score differences in the primary and secondary outcomes between the IG and CG did not render statistical significance (range of  $p = 0.108 - 0.595$ ).

After excluding clinical cases of anxiety and/or depression ( $n = 6$  in IG and  $n = 10$  in CG) a significant main intervention effect was found for NA  $F(1,46) = 5.60, p = .022$ , Cohen's  $d = 0.64$ . Univariate analyses revealed that those who completed the intervention had significantly lower NA at post-intervention  $F(1,59) = 4.24, p = .044$  and at 6-months follow-up  $F(1,57) = 4.62, p = .036$ .

Table 6. Results of the CET intervention on primary and secondary outcome measures. Mean and standard deviation (SD) of the four follow-ups and average mean scores for intervention group and control group. Between-group effect of Repeated measures ANCOVA.

Outcomes (min-max)	Postintervention		6 weeks		6 months		12 months		Average		Between-subject	
	IG <sup>a</sup>	CG <sup>b</sup>	IG	CG	IG	CG	IG	CG	IG	CG	<i>F</i>	<i>p</i>
<b>Anxiety</b> (0-21)	4.37 (4.27)	4.50 (3.57)	4.54 (4.35)	4.78 (4.28)	3.97 (4.19)	4.40 (3.75)	4.17 (3.72)	4.77 (4.23)	4.26 (4.13)	4.61 (3.96)	0.50	.483
<b>Depression</b> (0-21)	4.51 (3.66)	5.00 (3.69)	4.26 (3.02)	5.33 (4.41)	4.60 (3.64)	5.13 (3.92)	4.29 (2.96)	5.15 (4.00)	4.42 (3.32)	5.15 (4.01)	0.44	.511
<b>PA<sup>c</sup></b> (10-50)	31.61 (8.10)	30.47 (8.35)	31.35 (7.58)	30.28 (7.83)	30.65 (7.76)	30.36 (8.96)	30.68 (8.15)	31.31 (7.60)	31.07 (7.90)	30.61 (8.19)	2.65	.108
<b>NA<sup>d</sup></b> (10-50)	15.63 (6.52)	17.62 (6.04)	16.43 (6.32)	18.03 (7.34)	15.93 (5.87)	17.95 (5.82)	17.03 (7.29)	17.59 (5.89)	16.26 (6.50)	17.80 (6.27)	1.29	.260
<b>PHC<sup>e</sup></b> (0-400)	241.59 (84.61)	218.69 (94.25)	239.87 (88.03)	211.25 (102.63)	235.61 (91.32)	211.11 (96.29)	237.80 (94.93)	233.59 (101.05)	238.72 (89.72)	218.66 (98.56)	0.57	.452
<b>MHC<sup>f</sup></b> (0-400)	272.37 (88.32)	264.11 (93.77)	265.50 (90.04)	259.60 (95.81)	271.30 (78.80)	259.67 (90.68)	265.35 (94.72)	262.76 (102.00)	268.63 (87.97)	261.54 (95.57)	0.29	.595

<sup>a</sup> Intervention group, <sup>b</sup> Control group, <sup>c</sup> Positive Affect, <sup>d</sup> Negative Affect, <sup>e</sup> Physical Health Composite

of RAND 36, <sup>f</sup> Mental Health Composite of RAND 36

#### 7.4.1.2 *Illness perception and coping*

A main intervention effect was found for the appraisal of having personal control over the illness  $F(1,74) = 4.56, p = .036$ , Cohen's  $d = 0.36$ . The results from the univariate ANOVA showed a greater personal control in the IG at 6-week follow-up  $F(1,81) = 4.72, p = .033$ . The results were further confirmed in the analysis with PP with a main intervention effect  $F(1,68) = 8.19, p = .006$ , Cohen's  $d = 0.49$  and significance at 6-week follow-up  $F(1,74) = 6.69, p = .012$ .

With regard to coping styles, no main intervention effects were detected between the two randomization groups (range of  $p$  0.249 - 0.542). A significant interaction effect was shown in emotion focused coping  $F(3,204) = 2.83, p = .040$ . The IG had greater emotion focused coping up until 6 weeks and afterwards the CG increased emotion focused coping whereas it decreased in the IG.

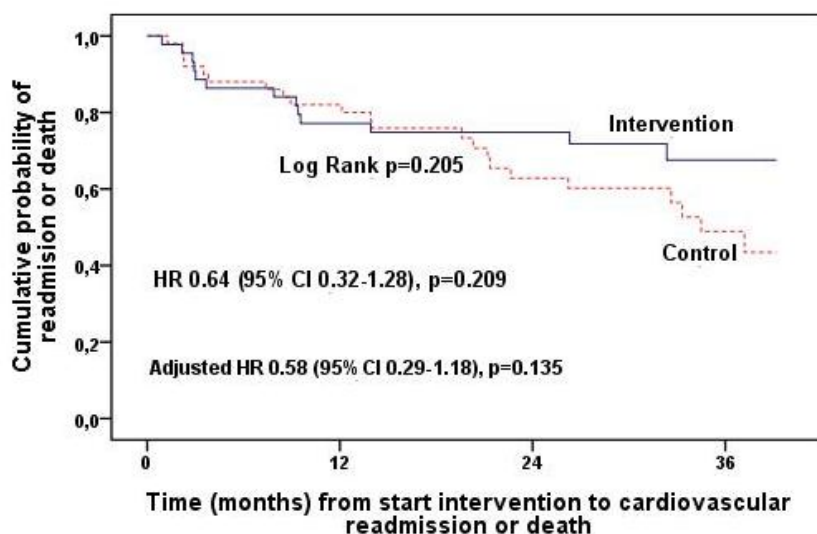
#### 7.4.1.3 *Social support*

When replicating the analysis adjusted for social support no new findings were found and the significant results revealed in the primary and secondary analyses remained.

### 7.4.2 **Clinical outcomes**

The tertiary outcome, readmission or death and total inpatient time from cardiovascular cause or all causes, were found to be non-significant between the randomization groups. Time to cardiovascular readmission or death were non-significantly lower in IG vs CG (HR 0.58 [0.29-1.18,  $p = 0.135$ ]) adjusted for age and sex as seen in Figure 7.

Figure 7. Kaplan-Meier curve for time to first cardiovascular readmission or death, with adjusted hazard ratio (HR) for age and sex. (The figure is from Paper IV in this thesis).



### 7.4.3 Patient reported experience

After completing the intervention the participants ( $n = 33$ ) filled in an anonymous written evaluation form of CET, which consisted of both closed and open-ended questions. The reported experience indicated that most of the participants considered they benefited from the intervention (94 %) and that they would recommend it to a friend (97 %). The participants' expectations before starting the CET varied between small (65 %) and great (45 %). The majority were pleased with the number (81 %) and length (79 %) of the sessions as well as the number of group participants (73 %). The free-text answers gave insight into what they explicitly thought they benefited from, such as the means to cope with CHF, acceptance of the illness and meeting other people with the same problems.

## **8 DISCUSSION**

### **8.1 GENERAL DISCUSSION**

The overall aim of this thesis was to gather scientific evidence regarding the influence of illness perception, coping strategies and sense of coherence on emotional well-being in patients with CHF. Furthermore, to establish a theoretically and empirically sound measurement model of coping strategies. Finally, to develop, implement and evaluate a nurse-led psychoeducational intervention for improving patients' adaptive coping skills, appraisal of the illness, emotional well-being, HRQoL and clinical outcomes.

#### **8.1.1 Influence of age, gender, NYHA class and SOC on coping**

In Study I it was hypothesized that NYHA class, age, gender and SOC would be associated with coping strategies used by patients with CHF. The hypothesis was to some extent confirmed mainly by negative associations via SOC and maladaptive coping strategies such as venting and self-blame. That is, the less an individual views their life situation as meaningful, comprehensible and manageable, the more likely the individual is to engage in these maladaptive coping strategies. This association has not previously been elucidated in patients with CHF, but similar results have been found in other groups of patients living with chronic illness<sup>212, 213</sup>. The result confirms the theoretical notion that SOC is a personal internal resource against life stressors<sup>162</sup>, such as living with CHF. In contrast, the result only partially supports Moos and Holahan's framework of coping with chronic illness, where also factors such as illness severity and demographic characteristics are proposed to influence the coping process<sup>123</sup>. The findings in Study I indicate that internal resources play an important role, rather than functional status and demographic factors, in how individuals with CHF cope with and adapt to their life situation.

#### **8.1.2 Measurement model for assessing coping styles**

Since different coping strategies have shown associations with adverse health outcomes in patients with CHF<sup>14, 127, 133</sup> it is important to have a reliable and valid



measurement instrument of coping that is also feasible to use in both research and clinical practice. Consequently, Study II aimed at examining higher order structures of a coping self-assessment instrument that has been widely used in patients with CHF, namely Brief COPE <sup>144</sup>. This unique and thorough examination revealed a four-factorial structure of Brief COPE, utilized in Study I, to possess the most adequate psychometric properties consisting of problem focused coping (active coping and planning), avoidant coping (denial, behavioural disengagement and substance use), socially supported coping (using instrumental support, using emotional support and venting) and emotion focused coping (positive reframing, acceptance, humour and religion). This four-factorial model of Brief COPE, utilized in Study I, derives from a higher order structure of COPE suggested by Carver et al. <sup>119</sup>. The higher order coping factors in the four factorial model of Brief COPE are supported by theoretical assumptions. Problem focused coping and emotion focused coping have been theoretically defined by Lazarus and Folkman's theory of stress and coping <sup>115</sup>. Carver et al. separated coping strategies generally viewed as maladaptive from the emotion focused coping factor and hence the avoidant coping factor was generated <sup>119</sup>. Carver et al. also suggested a socially supporting coping factor <sup>119</sup>. The dimensions of socially supported coping are, to some extent, supported by a conceptual framework of social support including instrumental support, emotional support, tangible support and appraisal support. The findings from Study II provide empirical support to the theoretically underpinned four-factorial model of Brief COPE in the context of CHF.

### **8.1.3 Influence of coping styles on emotional well-being and HRQoL**

The findings in this thesis indicates that greater use of avoidant coping worsens negative affectivity (Study I), depression, anxiety and malignant illness perception (Study III) as well as worsens HRQoL (Study II). Using avoidant coping means that an individual avoids thinking about a problem by denying it or constantly distracting him or herself from it with activities or by using substances. In this way an overwhelmingly stressful situation can be managed and the individual feels protected from the stressor <sup>214</sup>. CHF, in the light of its chronicity and poor prognosis <sup>15</sup>, could be seen as such an overwhelming stressor where the patient may resort to

avoidant coping to protect him or herself. In contrast, long term use of avoidant coping is more likely to be harmful than protective<sup>215</sup>. The findings in this thesis are supported by empirical research on avoidant coping in the context of CHF demonstrating adverse outcomes in emotional well-being and HRQoL<sup>14, 130, 132</sup>. Given the substantial evidence of the maladaptive nature of avoidant coping style in individuals with CHF, efforts should be implemented to identify patients who use this approach to deal with everyday life. Assessment with the four-factor model of Brief COPE (Study II) could be one such approach.

Besides the salient adverse influence of avoidant coping on emotional well-being and HRQoL in patients with CHF, this thesis presents some evidence of the influence of other coping styles on emotional well-being. In Study I, problem focused coping predicted positive affectivity, that is, if the individual engages in planning to actively solve a problem the individual will also feel better. For example, the individual with CHF might plan to divide one task across several days instead of doing it all on one day and as a result feel less pressure and save energy. There is some support for this finding in former research, indicating that problem focused coping has favourable effects on emotional well-being<sup>126, 216</sup> and daily activities, thus providing a sense of control<sup>135</sup>.

Somewhat unexpectedly, socially supported coping was found to predict negative affect although it was significantly correlated to both positive and negative affect. This result is inconsistent with previous research<sup>126, 217</sup>, however, a qualitative study found social support to both interfere and assist in coping with CHF<sup>218</sup>. A possible explanation for the result in this thesis might be explained by the inclusion of venting in the socially supported coping factor, as venting of emotions could be considered a maladaptive approach<sup>130, 153</sup>.

#### **8.1.4 Mediation model of avoidant coping and illness perception in anxiety and depression**

This thesis examined the theoretical underpinnings of the pathways between coping style, illness perception and emotional distress. The findings in Study III support the theory of dispositional coping, i.e. the coping style is rather stable over time and situations<sup>121, 219</sup>. This means that an individual with CHF who displays a

dispositional avoidant coping approach has a tendency to respond with avoidant coping in stressful situations, and thereby influence a malignant illness perception and increased emotional distress.

The findings in Study III showed a novel pattern between coping style, illness perception and emotional distress in patients with CHF which has not, to the author's knowledge, been revealed before. Avoidant coping style influenced anxiety and depression both directly and partly mediated by the patient's perception of control and illness burden. These results are, in part, supported by previous research showing negative associations between perceived symptom burden and personal control, with anxiety and depression as well as with behavioural disengagement considered as an avoidant coping strategy <sup>153</sup>. However, the previous research only supports correlational associations and not a mediating pattern between these variables, since this has never been explored before. Possible explanations for the mediating pathways found in Study III could be that avoidant coping influences the patients with CHF to be less likely to self-manage CHF. Consequently, the patient might experience more symptoms of CHF when, for example, not self-monitoring CHF symptoms. Lack of self-management has been found in research to be related to emotional distress <sup>220</sup>. Another explanation could be that avoidant coping asserts an adverse influence on self-efficacy, a control-related construct conceptually proximal to personal control, meaning the individual will have less confidence in engaging in self-management <sup>221</sup>. Low self-efficacy has been associated with greater anxiety and depression in patients with CHF <sup>64</sup>. The conceivable explanations can also be viewed in the light of the situation-specific theory of heart failure self-care where self-efficacy is highlighted as a personal factor that might influence the self-care process <sup>56</sup>. However, these possible explanations for the mediating pathways with regard to self-management in patients with CHF need to be investigated in empirical research.

### **8.1.5 Evaluation of a coping effectiveness training intervention**

In Study IV, a nurse-led coping effectiveness intervention for patients with CHF was evaluated. The theory based intervention, CET, consisted of training coping skills and appraisal of stress and was hypothesized to improve emotional well-

being, HRQoL and clinical outcomes. Changes in coping styles and appraisal of the illness, such as the perceived control and illness burden, were also examined since these factors were assumed to mediate the effect of the intervention on the outcome measures.

Although the PROMs of the primary endpoint (emotional well-being) and secondary endpoint (HRQoL) had a consistent pattern of improved average mean scores in line with the hypothesis of Study IV, they rendered non-significant. Previous research on a psychoeducational intervention for patients with CHF has shown reduced emotional distress during a 6-months period and improved HRQoL<sup>173</sup>. However, in the study by Sullivan et al.<sup>173</sup> the disease-specific Kansas City Cardiomyopathy Questionnaire (KCCQ) was used to measure HRQoL which has been proven to be a more sensitive instrument than, for example, SF-36<sup>222</sup> equivalent to RAND 36<sup>193</sup> utilized in Study IV.

When participants who self-assessed clinical scores on anxiety and/or depression as part of the primary endpoint were excluded from the analysis, a significant main intervention effect was found on reduced negative affect directly and six months after the CET for the participants who underwent the intervention. This result might indicate that the CET intervention is most suitable for patients with no or mild symptoms of anxiety and depression. Patients who suffer from more severe symptoms of anxiety and depression might need individual treatment; on the other hand, no negative effects for these patients were indicated. Previous research with a nurse-led depression care management provided in an individual-centered approach to reduce depression, showed positive results<sup>174</sup>. The finding in Study IV highlights that a group intervention might be favorable for an identified group of patients when it comes to efforts for reducing emotional distress.

The tertiary outcome, i.e. clinical outcomes as measured by readmission and death as well as total time for inpatient care cardiovascular cause and all cause, did not have a significant effect from the CET intervention. The result is consistent with former research<sup>173</sup>. Even though CET has been evaluated in other patient groups<sup>177, 178</sup>, clinical outcome measures have never been included in the evaluations. Since

Study IV evaluates clinical outcomes of the CET intervention for the first time the results contribute to unique information.

The CET intervention increased the perception of having personal control over the illness in the intervention group. This intervention effect was found after six weeks but was not sustained long term. Previous research has pointed out the perception of being in control as an important factor for individuals living with CHF, as it has been shown to be of importance in outcomes such as anxiety, depression, hostility, functional status and HRQoL <sup>153, 223</sup>. In Study III the perception of being in more control over the illness influenced a reduction in depression. Even though perception of control increased significantly in the intervention group depression did not significantly decrease, albeit a lower average mean score was found. This could be explained by the underlying mechanism elucidated in Study III where, apart from illness perception, avoidant coping style played a major role for emotional distress and avoidant coping was not impacted by the CET intervention. In fact, there was no main intervention effect for any of the coping styles. As discussed previously, the measurement of coping styles in this thesis appears to assess a rather stable form of coping style independent of time and situation <sup>121</sup>, therefore, it might be difficult to influence the coping styles. However, the emotion focused coping style demonstrated a significant interaction effect with time where, interestingly, the emotion focused coping increased in the control group whereas it decreased in the intervention group. According to the theory of stress and coping <sup>115</sup> emotion focused coping is an adaptive approach when individuals have less control over the situation and cannot solve the problem. Since CHF is a chronic condition that involves self-care management in order to maintain health, e.g. flexible diuretic intake, weight monitoring and physical exercise <sup>15</sup>, one could argue that emotion focused coping is a maladaptive approach. Because the intervention group had increased sense of control their need for emotion focused strategies to cope with their situation might have been less than it was for the control group.

Longer term positive effects of CET have been found when applied to patients with HIV, where an additional maintenance phase followed the completion of the CET sessions <sup>177</sup>. In order to achieve a sustainable longer term effect an additional

maintenance phase to the intervention design could, therefore, be suggested when applying it to patients with CHF. In addition, the CET could be further adjusted by incorporating training on specific strategies to prevent relapse in stress reactions as well as strategies to maintain new skills in coping and appraisal acquired during the CET.

Despite the modest intervention effect the participants' written evaluation, directly after completing the CET intervention, revealed satisfaction with the intervention and perceived benefits from the CET. For instance, meeting other people with CHF was seen as a positive experience. Indeed, meeting and having discussions with other people with CHF is an integral part of the CET intervention. However, it is not the only component of the CET taking into account the rigour and strengths of the intervention design being based on: a theory of stress and coping <sup>115</sup>, having an adapted manual and workbook, well thought through themes for every session and home assignments. The CET intervention appears to provide psychosocial support and, in its essence, teaches skills for psychosocial self-care. In Orem's theory of self-care the balance between self-care abilities and self-care deficits can be upheld in a nursing system, where a nursing system can support the patient in developing self-care abilities <sup>55</sup>. In the light of the theory of self-care the CET intervention could be viewed as a supportive nursing system, where the aim is for the patient to reach a psychosocial self-care balance.

## **8.2 METHODOLOGICAL CONSIDERATIONS**

In Studies I and III, the non-experimental cross sectional designs of the studies cannot empirically establish causality of the included variables in the analyses. However, the empirical data in the studies can provide consistency with the hypothesized and theoretical causality of the variables in the models <sup>224</sup>. In Study III, advanced statistical methodology with SEM extend the results beyond the purely correlational to provide a data-supported sound theoretical model of coping, illness perception and emotional distress <sup>209, 224</sup>.

The measurement of the coping styles in this thesis was indicated to assess dispositional coping, a rather stable form of coping. Hence, the theoretical models

in Study III should also be examined using measurements of situational coping<sup>115</sup> or domain specific coping, i.e. coping strategies varying in different life domains<sup>225</sup>. This could also explain why there was no significant intervention effect on the coping styles in Study IV.

In this thesis, a generic measurement of HRQoL was chosen<sup>193</sup>. The advantage with a generic instrument is that the results can be compared to those of healthy people or people living with other illnesses. RAND 36, utilized in this thesis, has been widely used to measure HRQoL<sup>102</sup>. Most of the patients with CHF also have co-morbidities to be taken into account<sup>226</sup> hence a generic HRQoL measurement could be more appropriate. Stating this, disease specific measurement of HRQoL in patients with CHF has proven to be more sensitive<sup>222</sup>.

Since there is no clear definition of emotional well-being it is consequently indistinct how the concept should be operationalized. In this thesis emotional well-being was measured by positive and negative affect, as well as by depression and anxiety. While affect is a recognized measurement of emotional well-being<sup>71</sup> one might argue that anxiety and depression measure emotional distress or possibly impaired emotional well-being. Nevertheless, emotional well-being and emotional distress are not entirely independent from one another but rather interact in a dynamic process<sup>81</sup>, therefore, it is important to measure both aspects to retrieve a broad picture of a person's emotional state.

The self-assessment questionnaires utilized in this study have shown good psychometric properties in the CHF population as described in the methods-section. However, the internal consistency as measured by Cronbach's alpha has been rather low for the higher order coping factors in the studies, except for avoidant coping and socially supported coping in Study I and problem focused coping in Study II. The higher order coping factors constitute broad theoretical constructs and therefore internal consistency might not be the optimal approach to measure reliability<sup>227, 228</sup>. Test-retest reliability could have been another approach<sup>229</sup>.

Due to novelty of the CET intervention, it was difficult to estimate a clinically relevant *a priori* effect size. The observed effect sizes, as measured by Cohen's d,

of the significant main intervention effects were in the range of small to medium, where Cohen's criteria for effect size regard  $\geq 0.2$  as small and  $\geq 0.5$  as medium<sup>230</sup>. It is possible that there could have been a potential lack of power for detecting a hypothesized intervention effect on the outcome measures in Study IV. Despite this, there were still some significant results found. The analyses were carried out firstly with ITT and secondly with PP. Analysis with ITT could enhance the risk of a type II error, whereas analysis with PP might introduce a biased treatment effect<sup>231</sup>. The randomization process should, however, reduce the risk of bias in allocation of randomization group<sup>232</sup> and there were no significant differences between the two randomization groups in this thesis.

The attrition rate was higher in the intervention group than in the control group at baseline. An explanation for this could partly be that the CET intervention required the participants to engage and commit during a two-month period, which may not have been possible for some owing to logistical reasons, illness or lack of energy. This could also explain why only 20 percent out of the eligible patients accepted to join the study, which could potentially be a selection bias. Consequently, the generalisability of the results is limited to patients with CHF who are physically mobile and in NYHA class II or III. The exclusion criteria also pose a limitation to generalisability, where the results cannot be generalised to patients with CHF who have a co-morbidity of another severe illness, psychiatric diagnosis or cognitive impairment, as well as to patients who can't speak the Swedish language. This limitation of generalisability also extends to the results of Studies I-III in this thesis.

When reporting a randomized controlled trial, transparency is crucial in order for the readers to understand its design, conduct, analysis and interpretation. Therefore, the Consolidated Standards of Reporting Trials (CONSORT) statement has been developed with a checklist and flow diagram for researchers to follow<sup>232</sup>. It was the author's intention to be as transparent as possible in this thesis when reporting the RCT in Study IV. This is particularly necessary since the author was involved in all stages of the study and had different roles, such as group leader, researcher and heart failure nurse. There were both strengths and limitations in having had multiple roles. The strengths were that being involved in all phases provided a



comprehensive overview, understanding and insight. The consistency of adherence to the study protocol was also most likely to have been enhanced when monitored by the same person. The participants might have had more confidence in the author as a group leader due to the author's multiple roles and, consequently, they may have experienced a safe environment during the sessions.

The limitations of having had several roles could be that the results from the evaluations of the intervention could have been influenced by the participants wanting to please the group leader/author of this thesis. Social desirability bias, when utilizing patient reported outcomes, and as a consequence threatening the validity of the results, has been discussed and evaluated in research but the results are inconclusive. Whereas some studies have pointed out the occurrence of social desirability bias <sup>233</sup>, a recent study has reported absence of social desirability bias when evaluating a chronic disease self-management intervention <sup>234</sup>. The strength of utilizing PROM is that it is a patient-centered method for evaluating an intervention. Furthermore, the endpoints or concepts measured with the self-assessment questionnaires in this thesis are subjective and can only be assessed by the patients themselves <sup>235</sup>. One could argue that an effect of the CET intervention is dependent on the group leader. This is somewhat controlled by standardization, as the group leader is following a manual when leading the sessions. The group leader should guide the discussions not dominate them. Therefore, the group leader kept in the background when the participants had a discussion amongst themselves.

## 9 CONCLUSIONS

Utilization of different coping strategies does not appear to be influenced by functional status, age or gender, but rather by personal resources such as sense of coherence in patients with CHF.

Avoidant coping style, i.e. denial, behavioural disengagement and substance use, is a maladaptive coping strategy for patients with CHF. Avoidant coping is associated with increased negative affect, depression and anxiety as well as worse HRQoL. Furthermore, avoidant coping appears to influence a malignant symptom perception and low sense of control over the illness.

The influence of avoidant coping on emotional distress is not only a straightforward link but is also mediated by perceived symptom burden and personal control over the illness, in individuals with CHF.

A four factorial structure of Brief COPE, a self-assessment questionnaire for measuring coping strategies, presented the best psychometric properties supported by theoretical assumptions and empirical data in patients with CHF. The structure consisted of avoidant coping, problem focused coping, emotion focused coping and socially supported coping.

A nurse-led group based intervention through CET seems to provide psychosocial support for patients with CHF. CET increased the sense of control at 6 weeks after the intervention. CET also reduced negative affect in patients with no or mild symptoms of anxiety and depression at post-intervention and at 6 months after the intervention.

## 10 CLINICAL IMPLICATIONS

Since avoidant coping has several adverse effects on health outcomes in patients with CHF, it is important to have approaches to identify avoidant coping. A four factorial assessment model of Brief COPE may facilitate the assessment of coping strategies in patients with CHF, compared to having 14 coping strategies to take into account.

Enhancing the patients' beliefs about personal control over the illness may contribute to improved emotional well-being in patients with CHF. Interventions that target both illness perception and coping are important in order to reduce emotional distress in patients with CHF. The CET intervention is a theory based intervention that provides evidence-based psychosocial support, and in extension, skills to engage in psychosocial self-care for patients with CHF in a systematic standard procedure.

A nurse-led coping effectiveness intervention is feasible to implement in clinical practice for patients with CHF in order to enhance personal control over the illness.

Patients with CHF who suffer from clinical depression and/or anxiety may need individual treatment, while the patients with mild or no symptoms of emotional distress might benefit from the group-based CET-intervention in reducing negative affectivity.

## 11 FUTURE RESEARCH

Longitudinal studies on the associations between coping, illness perception and emotional distress should be carried out in order to establish causality between these variables. For further clarification of the pathways self-management of CHF might be an important variable to measure in this context of research. Clinical outcome measures could also be examined in such studies in order to investigate the linkages between psychological and somatic variables. Furthermore, if these studies were equipped with sufficient power to enable subgroup analysis, potential differences between subgroups could be explored further.

Further research could be conducted regarding different designs of CET, such as an additional maintenance period to examine sustainable long-term effects, and online CET intervention. The purpose of the online CET intervention would be to make it accessible to a wider range of patients. Further controlled studies with CET intervention in patients with CHF, such as a multicenter study, should be carried out in order to verify and extend the results in this thesis.

Since the CET intervention is being applied for the first time to patients with CHF, additional qualitative evaluation of the CET intervention with interviews could be carried out in order to gather an in-depth knowledge of the participants' experience.

## 12 SVENSK SAMMANFATTNING

**Bakgrund:** Hjärtsvikt är ett allvarligt och obotligt syndrom som drabbar ungefär två procent av befolkningen och prevalensen ökar med stigande ålder, där mer än 10 procent av befolkningen över 70 år har hjärtsvikt. Prognosen och symptom-bördan vid hjärtsvikt är jämförbar med många cancerdiagnoser. Personer som har hjärtsvikt har sämre hälsorelaterad livskvalitet jämfört med normalbefolkningen i samma ålder och förekomsten av depression och ångest är hög. Forskning har visat att sämre hälsorelaterad livskvalitet, depression och ångest predicerar en ökad dödlighet och återinläggning på sjukhus hos patienter med hjärtsvikt. Trots detta uppmärksammas sällan psykosociala aspekter och de får följaktligen ingen vård och behandling för detta. Coping (stresshantering), d.v.s. hur en person bedömer och bemästrar en stressfylld situation, som individen tillämpar för att t.ex. anpassa sig för att leva med hjärtsvikt, och sjukdomsuppfattning har visat sig i forskning ha betydelse för det emotionella välbefinnandet.

**Syfte:** Det övergripande syftet med avhandlingen var att samla vetenskaplig evidens hur sjukdomsuppfattning, coping och känsla av sammanhang påverkar emotionellt välbefinnande hos patienter med hjärtsvikt. Samt att fastställa en teoretisk och empiriskt grundad mätmodell för att mäta copingstrategier. Vidare att utveckla, implementera och utvärdera en sjuksköterskeledd psykosocial intervention i syfte att förbättra patienternas adaptiva copingförmåga, sjukdomsuppfattning, emotionella välbefinnande och hälsorelaterade livskvalitet samt att minska återinläggning på sjukhus.

**Metoder:** Studierna I-III hade en tvärsnittsdesign. Studie I undersökte vilka faktorer som kan inverka på coping och hur coping inverkar på emotionellt välbefinnande. Studie II var en metodologisk studie som undersökte en högre faktorstruktur av Brief COPE, ett självskattningsformulär som mäter copingstrategier. Studie III analyserade två uppställda hypotetiska modeller av medierande effekt av coping och sjukdomsuppfattning på depression och ångest. Studie IV var en randomiserad kontrollerad studie där en psykosocial intervention, Coping Effectiveness Training (CET), anpassat till patienter med hjärtsvikt utvärderades under ett år efter avslutad intervention. Det primära utfallsmåttet var emotionellt välbefinnande, det

sekundära utfallsmåttet var hälsorelaterad livskvalitet och det tertiära utfallsmåttet var återinläggning på sjukhus och död. Alla studier använde patientrapporterade data och kliniska data inhämtades via patienternas medicinska journaler.

**Resultat:** Känsla av sammanhang var negativt associerat med dysfunktionella copingstrategier. Yngre ålder och manligt kön var signifikant associerat med högre användning av alkohol och/el droger som copingstrategi ( $p < 0.01$ ) (I). En fyrfaktor-modell av Brief COPE innehållande problemfokuserad, känslfokuserad, socialt stödjande och undvikande coping visade sig ha bäst psykometriska egenskaper (II). Högre grad av användande av undvikande coping, t.ex. förnekande eller ägna sig åt distraherande aktiviteter för att inte behöva ta itu med sin situation, var signifikant associerat med högre nivåer av negativ sinnesstämning (I), och ångest och depression (III) samt sämre hälsorelaterad livskvalitet (II). Undvikande coping visade sig även påverka en lägre känsla av kontroll samt högre uppfattad sjukdomsbörda, vilket i sin tur gav högre nivåer av ångest och depression (III). CET (IV) förbättrade känslan av kontroll över sin sjukdom hos de deltagare som randomiserats till interventionsgrupp (IG) jämfört med de deltagare som randomiserats till kontrollgrupp (KG) ( $p = 0.036$ ). Förbättrade medelvärden på emotionellt välbefinnande och hälsorelaterad livskvalitet upptäcktes också hos IG jämfört med KG men skillnaderna var inte statistiskt signifikanta. När patienter som hade kliniska nivåer av ångest och/el depression exkluderades, visade det sig att negativ sinnesstämning minskade signifikant hos IG jämfört med KG ( $p = 0.022$ ). Tid till kardiovaskulär återinläggning eller död var icke-signifikant lägre hos IG än hos KG, HR 0.58 (0.29-1.18), kontrollerat för kön och ålder.

**Slutsatser:** Inre resurser snarare än ålder, kön och allvarlighetsgrad i hjärtsvikten, inverkar på coping hos patienter med hjärtsvikt. En fyrfaktormodell för att mäta copingstrategier visade sig vara en reliabel och valid modell för att underlätta mätningen. Undvikande coping har en ogynnsam inverkan på emotionellt välbefinnande och känslan av kontroll samt sjukdomsbörda. CET visade sig öka känslan av kontroll över sin sjukdom hos patienter med hjärtsvikt. Dessutom minskade CET negativ sinnesstämning hos de individer som inte hade måttlig till svår ångest och/el depression.

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